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Assessing Patient Perceptions of Self-Care: Examining Chronic Disease  
in an Underserved Rural Area

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Education in Adult and Lifelong Learning

by

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August 2017  
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This dissertation is approved for recommendation to the Graduate Council.

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**Abstract**

The Affordable Care Act of 2010 mandated healthcare reform in the United States by requiring insurance coverage for more Americans. Further, the law deemed healthcare providers, communities and individuals throughout the nation were responsible for fighting chronic disease and escalating healthcare costs. Preventive care and self-care have been cited as low-cost options for initiating change in the American population by helping individuals have access, information and resources to make better healthcare choices and manage their chronic diseases. The purpose of this ethnographic study was to identify the perceptions of self-care from patients living with chronic disease in an underserved, rural area.

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## **Acknowledgments**

Special thanks to Dr. Kit Kacirek, for your support and direction throughout this experience. Thank you for reminding me whenever I got lost in the details that you could see the big picture. Your instruction, guidance and example have shown me the beauty of learning in all stages of life.

Also, special thanks to Dr. Theres Stiefer, for your valuable classes on program planning and educational leadership. Your positive attitude and kind words were always appreciated, as was your advice to approach the literature review in small, doable sections.

In addition, special thanks to Dr. Vicki Dieffenderfer, for your support and direction whenever I had questions about my methodology, as well as spending hours helping me analyze and code my interviews. You are an infectious and kind person, and I am extremely grateful for your insights and help.

To my ADLL cohort, I am honored to have had the opportunity to go on this journey with you. You are some of the most talented, intelligent and amazing individuals I have ever met. Your help and suggestions were invaluable, and I expect to hear great things about your future accomplishments.

To Annette Wells and Dr. Tom Martin in the PCRMC Heart & Vascular Center, thank you for allowing me to disrupt your clinic on multiple days with questions and patient interviews. I could not have completed this research without your kindness, expertise and generosity.

To my in-laws, Bob and Linda, thank you for your love, support and always

providing me with “traveling money.”

To Lindsey Dunstedter, my good friend and editor extraordinaire, thank you for editing my work over the last several years. You taught me every good writer needs a good editor. I am indebted to you for your talent, graciousness, friendship, encouragement and persistent “cutting.” My writing is stronger because of you.

To Shannon and Sandon, thank you for your love and great sense of humor when I needed to laugh the most. I love you.

To Mom, thank you for believing in me throughout my life. On my circuitous route to achieving my educational goals, you were beside me every step of the way, encouraging me and cheering me on. You never gave up on me, even when I wanted to give up on myself. My admiration and love for you is limitless.

To Brandon, your support and encouragement all of these years is immeasurable. Your love kept me afloat and gave me the strength and stability to keep going. Our life together is one of my greatest blessings.

To Abigail and Ethan, you are my heart and joy. Remember to never give up on your goals in life. Life happens, detours are taken, but the end result is worth it. Keep moving forward. I will be cheering you on.

Finally, to God, you are my constant source of hope and purpose. Thank you for giving me the chance to complete this journey. I pray you will continue to direct my path; grant me the opportunities to use this experience to help other people throughout my lifetime.

**Dedication**

For Dad, with love. You are missed.

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## **Chapter 1**

### **Overview of Problem**

#### **Background of the Study**

The Affordable Care Act (ACA) of 2010 mandated a nationwide initiative to address chronic disease through prevention in the United States. Healthcare costs continue to rise, largely due to the increase of chronic disease rates throughout the country (Centers for Disease Control and Prevention, 2017). The Centers for Disease Control and Prevention lists the top four causes of death in the United States as the following: (1) heart disease; (2) cancer; (3) chronic lower respiratory disease; and (4) stroke (2010). Many of these conditions are the result of untreated or unmanaged chronic diseases, and 86% of all healthcare dollars in the United States are spent on treating chronic diseases (Centers for Disease Control and Prevention, 2014).

As part of the ACA, the National Prevention Council released the National Prevention Strategy in 2011 which highlighted areas and ways to improve the health and wellness of the American population through prevention (National Prevention Strategy, 2011, p. 3). The National Prevention Strategy is divided into four strategic initiatives, including: (1) healthy and safe community environments; (2) clinical and community preventive services; (3) empowered people; and (4) elimination of health disparities (National Prevention Strategy, 2011, p. 3).

The National Prevention Council is directed by the United States Surgeon General and comprised of 20 federal departments, agencies and offices. The National Prevention Council created the National Prevention Strategy based on recommendations from the public, key stakeholders and the Prevention Advisory Group. The effort was designed to engage a diverse range of departments within the National Prevention Council, such as "housing, transportation, education, environment and defense" to take steps to "ensure the health, well-being and

resilience of the American people" (Surgeon General, n.d.).

In addition to the ACA's goal to provide more Americans with health insurance, another way the ACA is addressing the unmanaged and untreated chronic disease driving up healthcare costs in the United States is to implement community outreach opportunities to encourage Americans to seek preventive care and make healthy choices a lifelong priority. The National Prevention Strategy notes healthcare prevention and empowering people are evidence-based (patient care and treatment plans derived from a multi-disciplinary approach, national benchmarks and clinical trials), effective and low-cost measures to help eliminate health disparities. While prevention services are often clinically based, meaning the services involve direct patient care, health information can be delivered across numerous platforms, including communities, workplaces, schools and residences (National Prevention Strategy, 2011, p. 18). Access to community, group (e.g. support groups, community health teams, workplace initiatives) or individual (one-on-one) support-based programs or strategies may improve individual motivation for self-care and help negate barriers to assist individuals and families in making healthier lifestyle choices (National Prevention Strategy, 2011, p. 18).

Chronic diseases and acute diseases differ in that acute diseases occur suddenly, and are often "accompanied by distinct symptoms that require urgent or short-term care" (National Council on Aging, 2016, p. 2). Acute conditions tend to get better when treated, and people with acute conditions (such as a broken bone, flu, pneumonia, etc.) often recover (National Council on Aging, 2016, p. 2). In contrast, chronic diseases are conditions that "are slower to develop, may progress over time, and may have any number of warning signs or no signs at all...Unlike acute conditions, chronic health conditions cannot be cured—only controlled" (National Council on Aging, 2016, p. 2).

While chronic diseases in the United States are “the most common and costly of all health problems, they are also the most preventable” (Centers for Disease Control and Prevention, 2009, p. 8). Prevention is vital to combating chronic disease. According to the Centers for Disease Control and Prevention (2016), prevention must occur throughout life, and includes “health promotion activities that encourage healthy living and limit the initial onset of chronic diseases..., early detection efforts, such as screening at-risk populations, as well as strategies for appropriate management of existing diseases and related complications” (p. 8).

### **Statement of the Purpose**

Gardner (2014) noted the goals of the ACA were to improve patient health outcomes through increased access and better management of care while managing resources and funding low-cost options. Gardner additionally stated access to information alone does not change patient behavior; rather, healthcare organizations must implement change through patient and provider collaboration. Data indicates rural residents often have limited access to health resources where chronic conditions are prevalent (Missouri Hospital Association, 2013). Rural residents are also more likely to die from chronic conditions than urban residents, and these deaths from chronic diseases in rural areas are often “potentially preventable” (Centers for Disease Control and Prevention, 2017, p. 1). Several factors have impeded research in rural areas, including lack of funds and the availability of a trained workforce (Baba, Brînzaniuc, Sirlincan, & Chereche, 2010); the difficulty of recruiting rural, underserved participants for research (Young, Barnason, & Do, 2015; Miyamoto, Ward, Santillan, Henderson, & Young, 2013); shortage of available healthcare providers (Missouri Hospital Association, 2011); long distance travel to healthcare facilities; and the “need for improved public health programs...or better access to health care services” (Centers for Disease Control and Prevention, 2017, p.1).

To better understand the issues associated with managing chronic disease in rural areas, the present study examined the perceptions of rural residents with congestive heart failure about the motivators or inhibitors for implementing self-care at home. The study elicited participant responses from a series of structured, one-on-one interviews to determine a potential hospital policy or community-based education plan that ensures rural residents living with a chronic condition have access to the knowledge and tools necessary to effectively self-manage their disease.

Heart failure is a chronic disease that affects 5.7 million Americans (American Heart Association, 2015). Heart failure becomes congestive heart failure (CHF) when “fluid builds up in various parts of the body” (American Heart Association, 2015, p. 1). Heart failure symptoms are exacerbated over time as the heart becomes weaker and cannot pump blood efficiently throughout the body. Heart failure usually causes the left ventricle to become enlarged, and the condition gets worse when not treated (American Heart Association, 2015).

Symptoms of heart failure include, shortness of breath, fatigue, “coughing or wheezing when lying down or exercising, swelling in feet, ankles and legs, [and] weight gain from fluid buildup” (American Heart Association, 2015, p. 1). Best practices for self-managing heart failure include the following: taking prescribed medications, weighing daily to check for fluid weight gain, tracking daily fluid intake, taking blood pressure daily, limiting alcohol and caffeine, losing weight (if needed), following a heart-healthy diet low in sodium, eating fewer salty or sodium-filled foods, exercising and getting plenty of rest (American Heart Association, 2015).

### **Research Question**

The study addressed the following research question:

1. How do congestive heart failure patients living in a rural area perceive their ability to perform self-care measures at home?

### **Theoretical Framework**

The present study examined rural congestive heart failure patients' perceptions on their ability to self-manage their chronic condition at home. The conceptual framework for this study was derived from the nationwide initiative, spearheaded by the ACA, to enact health and wellness programs within individual residences, workplaces and communities. Healthcare can be a confusing landscape, and many people do not have the necessary access to receive much needed health education, resources and guidance (Mead, 2010). People living in rural or low-socioeconomic areas may have further health disparities, which may include limited education, finances, and access to health and wellness resources. Due to these disparities, the rural population may be unable to receive needed, quality healthcare services and/or preventive exams (Centers for Disease Control and Prevention, 2017; Missouri Hospital Association, 2014; Mead, Andres, Ramos, Siegel, & Regenstein, 2010).

The present study incorporated the Heuristic Elicitation Methodology (HEM), as described in Nardi & Harding (1978), to identify patient perceptions of the motivating and inhibiting factors of taking self-care measures at home. Using the HEM, participants were asked a series of inter-related questions in order to determine how they perceived their ability to perform self-care measures at home.

### **Significance of the Study**

According to the ACA, the United States healthcare system is in need of reform to enable all Americans to gain access to healthcare coverage, resources, and wellness and prevention

initiatives. Concurrently, healthcare reform needs to offset the rising healthcare costs due to the prevalence of chronic disease (Thorpe, Odgen, & Galactionova, 2010).

The significance of this ethnographic study was to identify the healthcare needs of patients living with congestive heart failure in an underserved, rural area in order to help them better self-manage their chronic conditions at home. A sub-significance was to help healthcare organizations and hospitals identify what does and does not work when implementing a preventive or self-care program or policy in a hospital, which may or may not include health or wellness coaching, informational and educational sessions and community partnerships.

There is limited research on the potential areas to bridge the gap between receiving healthcare information and resources in a hospital or clinic and the motivation to perform self-care at home with underserved, rural residents. The literature suggested a lack of research in rural areas may be due to a number of factors, including lack of funding, resources and workforce (Baba et al., 2010); lack of ability to recruit rural participants (Miyamoto et al., 2013); and lack of community involvement or support (Olden & Szydlowski, 2004).

## **Research Design**

The present study used a qualitative research design, because qualitative studies seek to make meaning of a “social or human problem” by examining people or individuals in a natural setting (Creswell, 2013, p. 44). Specifically, this study utilized an ethnographic design, as ethnography focuses on a culture-sharing group to determine the group’s attitudes, beliefs and ideas about a certain phenomenon. In an ethnographic design, the researcher is an active participant in the data collection and discovers specific themes and shared values of a specific group (Creswell, 2013, p. 90).

Further, this study incorporated the Heuristic Elicitation Methodology (HEM) as described in Nardi and Harding (1978). The HEM is an ethnographic research method that examines a specific, culture-sharing group and extracts the group's ideas, values and beliefs, which are preserved in their native language (Harding & Livesay, 1984). The intrinsic language is conserved by asking a series of systematic, interlinked questions, including probe questions, about a "particular area of interest (or domain)" (Nardi & Harding, 1978, p. 39). The verbatim preservation of a culture-sharing group's native language helps ensure the validity of the HEM (Nardi & Harding, 1978; Harding & Livesay, 1984).

### **Role of Researcher**

At the time this research was conducted, I was employed as a senior public relations specialist in the Marketing and Public Relations Department at a healthcare organization in Rolla, Missouri. As a working professional in the healthcare industry, I brought insight to the study from a non-clinical healthcare perspective, which means I was not directly involved in patient care, but I had knowledge as to how there is often a communication gap between patients and healthcare professionals. In the marketing profession, your job is to target a specific audience to utilize or purchase a product. Healthcare has become a buyers' market, and just like other commodities on the market, buyers have a choice about where they go to purchase their health services.

My job in marketing was to inundate the public (through social media, web, print and radio) with information about the available resources, treatments, services, education classes and healthcare providers available through our facility. Even with all of the health information readily available, people still would not change their healthcare behaviors, such as establishing a relationship with a primary care provider versus utilizing the emergency room for primary care.



In our healthcare organization's service area, 28.4% self-reported they did not have an established primary care provider, which is a higher percentage than in Missouri at 20.6% and the United States at 22.1% (Community Health Needs Assessment, 2016, p. 21). Individuals still would not schedule exams or preventive tests, even though these resources were available to them at reduced or no-cost, if needed. Patients with chronic conditions would not be successful in making any lasting lifestyle changes, and they would end up being readmitted to the hospital (Community Health Needs Assessment, 2016).

Based on the aforementioned reasons, I have witnessed that even with information readily available, people will often not utilize these available resources, which corroborates what Gardner (2014) suggested: providing people with resources alone does not change behaviors. There continues to be a gap between information, access and change, and I believe we need to focus within these gaps to help people initiate and sustain change.

### **Assumptions**

Based on my work and experience in healthcare, three assumptions guided this study. First, rural patients often do not change their behaviors when diagnosed with a chronic diseases; they may understand they have a chronic condition, but they may not be cognizant of the disease's effects, its implications on their lifestyles, or the steps they must take to self-manage their condition. This lack of understanding or motivation to change may be due to several factors that include, lower education levels in a rural community; a lower median income in a rural area; and an older demographic of many people with chronic conditions.

These factors may impede patients' abilities to make lifestyle changes, because due to education level, they may not understand what their healthcare provider is telling them at a doctor's appointment, but they may be too proud to ask. Or, if patients have a lower income,

they may not be able to afford the better foods or medications they need to combat their disease. Lastly, older individuals may not have access to online resources; they may not have a computer or even know how to use one, which could mean these adults may not have access to the health information readily available online. Also, older adults may not have good social support (significant others, family members, friends) and may delay seeking medical attention until symptoms have progressed (Graven, Grant, & Gordon, 2015).

The second assumption that guided this study was that although patients may have the desire to change, they might not know what steps to take to initiate change. A chronic condition can be overwhelming, and upon diagnosis, patients may not understand their conditions, how to start making positive lifestyle changes, or how to include these lifestyle changes into daily activities (Mead et al, 2010).

My third assumption regarding the self-care of chronic conditions was many patients with chronic conditions are not able to make, or sustain, lifestyle changes if they do not have a support system. If they do not have friends, family or an established relationship with a trusted healthcare provider, then change likely will not be sustainable over a long period of time (National Prevention Strategy, 2011; Clark, Freydborg, McAlister, Tsuyuki, Armstrong, & Strain, 2009).

### **Definition of Terms**

**Affordable Care Act.** The health reform legislation passed by the 111<sup>th</sup> Congress and signed into law by President Barack Obama in March 2010. Key provisions include extending coverage to millions of uninsured Americans, implementing measures to lower healthcare costs and improve system efficiency, and to eliminate industry practices that include rescission and denial of coverage due to pre-existing conditions (Healthinsurance, n.d.).

**Chronic Disease.** A long-lasting condition that can be controlled and managed but not cured. Examples of chronic disease include arthritis, heart disease, hypertension, obesity, diabetes, chronic pulmonary respiratory disease, cancer, stroke and depression.

**Health Disparities.** Health disparities occur when a health outcome "is seen to a greater or lesser extent between populations" (U.S. Department of Health and Human Services, 2017). For the context of this paper, a health disparity was defined as a greater or lesser extent of chronic disease between rural and urban communities.

**Heuristic Elicitation Methodology (HEM).** A research methodology used to identify the attitudes, perceptions and beliefs of a group of people. The HEM uses a "series of interlinked questions in which responses to one question determine the form of subsequent questions" (Nardi & Harding, 1978, p. 39). The HEM is structured into three data collection phases and incorporates qualitative and quantitative methods.

**Cover Terms.** Cover terms, according to Spradley (1979), are names for things, or "are names for a category of cultural knowledge. *Tree*, for example, is a cover term in English for a larger category of knowledge, the various types of trees such as oak, pine, and yew" (p. 100).

**Included Terms.** Spradley (1979) identified included terms as "folk terms that belong to the category of knowledge named by the cover term" (p. 100). For example, "'We planted an elm, an oak, and three pines in our yard last summer.' This usage suggests that elm, oak, and pine might all go together as included terms in some domain" (p. 100).

**Semantic Relationships.** Spradley (1979) identified semantic relationships as "when two folk categories are linked together" (p. 100). For example, an elm (included term) is a kind of tree (cover term).

**One-On-One Interview.** A data collection method where the researcher asks an individual a series of pre-established, open-ended questions and records the participant's responses.

**Preventive Care.** Preventive care is a type of care that adopts preventive measures and health screenings such as routine physicals; well-baby and well-child care; immunizations; diagnostic lab and x-ray tests; pap smears; mammograms; and other early detection testing which is often covered in a health plan. (USLegal, n.d.)

**Self-Care.** Self-care is a purposeful action an individual takes to promote or maintain good health. The World Health Organization (2009) notes self-care varies depending on social factors and health conditions.

### **Delimitations of the Study**

The following delimitations were presented for this study:

1. The study only included rural residents receiving care at a healthcare facility in Rolla, Missouri. Individuals living in urban and other rural areas were not studied.
2. The study only included congestive heart failure patients enrolled in the congestive heart failure clinic at a healthcare facility in Rolla, Missouri. Congestive heart failure patients not enrolled in the heart failure clinic were not studied.
3. The study only examined patients living with congestive heart failure and did not examine other chronic conditions.
4. The study only included patients living with congestive heart failure for one year or more. Patients who were diagnosed with congestive heart failure for less than one year were not studied.

5. The study only included 10 participant interviews, instead of the 13 or more often used in the Heuristic Elicitation Methodology.

## **Summary**

The ACA (2010) shifted the healthcare landscape in the United States by requiring insurance coverage for more Americans. In addition, the ACA called for healthcare reform by addressing the prevalence of chronic disease and the continued rising healthcare costs in the nation. While preventive care is a cost-effective and evidence-based practice, Americans with health disparities may not have the access, information, resources or tools to effectively make informed healthcare choices to better manage their chronic diseases (American Hospital Association, 2011).

The present ethnographic-study examined the perceptions of rural residents living with congestive heart failure and the potential motivators and barriers of managing self-care measures at home. The study incorporated the Heuristic Elicitation Methodology (HEM), which elicits responses from a culture-sharing group in order to identify potential areas for reform in community education programs, as well as healthcare and hospital policies.

## **Chapter 2**

### **Review of the Literature**

#### **Overview**

The purpose of this ethnographic study was to examine the perceptions of 10 congestive heart failure patients who lived in a rural area about their ability to provide self-care for their chronic condition at home. The following literature review guided the research by offering an understanding of the interconnectedness among rural residents, chronic disease and self-care. Within the research parameters of rural residents, chronic disease and self-care, five major topics were examined, including the Patient Protection and Affordable Care Act (PPACA), chronic disease, preventive and self-care, rural residents and health disparities, and the Heuristic Elicitation Methodology (HEM).

#### **Search Strategies and Terms**

EBSCOhost, Proquest and PubMed databases were searched using the University of Arkansas libraries. GoogleScholar and Eric search engines were also used to identify relevant literature outside of the University of Arkansas's libraries. The search terms used included a combination of the following: Patient Protection and Affordable Care Act (PPACA); Affordable Care Act (ACA); rural; disparity; communities; remote; prevention; preventive care; self-care; self-management; chronic disease; Heuristic Elicitation Methodology (HEM); healthcare and chronic disease management. The Boolean operator "and" was used to combine the search terms in numerous ways. Search parameters included the years 2010 to present. 2010 was used as a starting point, because the ACA was implemented the same year. Seminal studies were not restricted to the year search limit.

#### **The Patient Protection and Affordable Care Act**

The Patient Protection and Affordable Care Act, hereafter the Affordable Care Act

(ACA) of 2010 drastically shifted the healthcare landscape in the nation. The ACA called for reform in key areas, including extending coverage to millions of uninsured Americans; implementing measures to lower healthcare costs; and increasing access and improving overall healthcare system efficiency (Smith, Lake, Simmons, Perlman, Wroth, & Wolever, 2013). The ACA specified the need for change through prevention and prevention resources. The ACA advocated the need for accessible and free preventive care services, such as screening and wellness exams, for all Americans as a mechanism for earlier detection of chronic diseases and/or comorbidities. The premise for encouraging preventive health services is twofold: (1) early detection means better care coordination and opportunity for education; and (2) early detection eases the burden of healthcare expenditures due to the exacerbation of chronic conditions and comorbidities in end-of-life stages (Shi, Nellans, & Shi, 2015).

The National Prevention Council was developed to supplement the ACA by “building on the law’s efforts to lower healthcare costs, improve the quality of care and provide coverage options for the uninsured” (National Prevention Strategy, 2011, p. 6). Hence, the ACA National Prevention Strategy (2011) identified four areas of focus to ensure and encourage healthy people and communities, which include healthy and safe communities environments; clinical and community preventive services; empowered people; and elimination of health disparities. The National Prevention Strategy (NPS) initiative of empowering people acknowledged people must be engaged in their health to have a healthier future. In addition, the NPS recognized people make decisions based on a myriad of reasons, some of which include "personal, cultural, social, economic, and environmental factors" (p. 22). These factors affect people's ability and motivation to take control of their own health. To that effect, the NPS outlined areas for health improvement for individuals and communities throughout the United States.

Although the ACA called for national healthcare reform, implementing reform measures to prevent disease and reduce costs for all Americans is problematic (Chokshi & Farley, 2012; Freudenberg & Olden, 2011). While some of the literature argued the American healthcare landscape has shifted to a “population health and prevention” climate that targets people’s active participation in their own healthcare (Corbett & Kappagoda, 2013, p. 17), other literature claims the U.S. healthcare system remains stationary as an environment of diagnosis and treatment, with a lack of focus on prevention and maintenance (Kemp, 2012).

While the goal of the ACA was to benefit all Americans through healthcare reform, Kemp (2012) argued as the U.S. population continues to age, chronic health conditions, disability, death and continued rising healthcare costs will continue if the U.S. health mindset does not seriously focus on prevention to reduce chronic illnesses and health disparities (p. 1-4). The NPS acknowledged simply giving people health and wellness information is not enough to incite change. Numerous internal and external factors influence people’s motivation and knowledge to change their health behaviors. The NPS suggested information and access to resources must be coupled by a support system, both personal and through healthy community partnerships (p. 22).

Literature examining the ACA’s impact on the American healthcare system is only now beginning to emerge. Adepoju, Preston, and Gonzales (2015) noted even though the ACA has been implemented for several years now, there is still "a wide chasm in health care access, quality and outcomes" (p. S665). The authors further identified the underutilizations of preventive healthcare services and screenings as a continued "barrier to reducing the chronic disease burden" (p. S666). Preventive healthcare services are tests, screenings, vaccinations, patient counseling and regular visits to a primary care provider; participation in these activities



are used to “prevent illnesses, disease, and other health problems, or to detect illnesses at an early stage when treatment is likely to work best” (Centers for Disease Control and Prevention, 2015, p. 1). The authors cited cost as a continued obstacle as to why people do not seek healthcare prevention services, and noted even wealthier populations underuse prevention services if they have to pay for the service out-of-pocket (p. S666). In order to reduce underutilization of healthcare preventive services, the authors identified education on the "importance and availability" of preventive care is vital; these sessions could be delivered via community health workers or peer counselors. (p. S666).

Torres, Poorman, Tadepalli, Schoettler, Ho Fung, Mushero, Campbell,...& McCormick (2017) designed a quasi-experimental study to identify whether the implementation of the ACA significantly impacted insurance coverage, healthcare access and health disparities for Americans living with chronic disease. The authors acknowledged previous research “conducted in the first 18 months of the ACA’s primary reforms found that for the U.S. population as a whole, the ACA resulted in increases in health insurance coverage, with smaller improvements noted for health care access” (Torres et al., 2017, p. 472). However, the authors asserted, limited information is available on whether the ACA increased access to care or insurance coverage for Americans living with chronic conditions.

The authors used data collected from Behavioral Risk Factor Surveillance System (BRFSS), a telephone survey conducted by state health departments and the Centers for Disease Control and Prevention (CDC), which examines American residents’ perceptions on “health conditions, access to care, health insurance coverage, and demographic characteristics for the adult population of each state” (Torres et al., 2017, p. 473). The authors examined data on 606,277 adults, aged 18 to 64 years, who reported at least one chronic disease. The variables

measured included whether or not the respondent had health insurance, a primary care provider, a recent (within the last year) preventive care checkup, and if the respondent had to miss a health appointment due to cost (Torres et al., 2017, p. 473).

Overall, the authors found the ACA improved insurance coverage and preventive care checkups and decreased the cancellation of scheduled healthcare appointments due to cost. The study showed no improvements in establishing care with a primary care provider (p. 477). However, the study showed “insurance coverage and having a routine checkup improved to a greater degree in Medicaid expansion states than nonexpansion states” (Torres et al., 2017, p. 477). In addition, the authors noted insurance coverage and healthcare access for Americans living with chronic conditions “remained substantial, particularly for racial and ethnic minorities and for persons residing in states that did not expand Medicaid” (Torres et al., 2017, p. 477).

### **Chronic Disease**

In the United States, chronic disease is prevalent and continues to rise: one out of every two adults in the nation has at least one chronic condition (Torres et al., 2017; National Prevention Strategy, 2011; Centers for Disease Control and Prevention, 2009). Chronic disease is responsible for 70% of deaths in the U.S., as well as health problems, disabilities and healthcare costs (Bauer, Briss, Goodman, & Bowman, 2014; Harris & Wallace, 2012). Chronic disease is such a critical problem within the U.S. health system that the Centers for Disease Control and Prevention (CDC) labeled chronic disease “the public health challenge of the 21st century” (Centers for Disease Control and Prevention, 2009, p. 1).

### ***Preventive Healthcare***

With the implementation of the Affordable Care Act in 2010, healthcare in the U.S. began to focus more on prevention and detection, as well as healthcare education opportunities

(Bauer et al., 2014; Freudenberg & Olden, 2011) in an effort to circumvent the burden of the American chronic disease epidemic. According to Koh and Sebelius (2010), health reform and promotion is needed, as “Americans receive only about half of the preventive services that are recommended” (p. 1).

Preventive healthcare services include “screening tests, counseling, immunizations or medications used to prevent disease, detect[ing] health problems early, or provid[ing] people with the information they need to make good decisions about their health” (National Prevention Strategy, 2011, p. 18). The National Prevention Strategy (2011) asserted the amount of preventive services used in the United States is correlated to Americans’ understanding the “benefits of preventive care and their motivation and ability to access services” (p. 18). Further, the National Prevention Strategy emphasized the need for “clinical, community, and complementary [health] services” to be integrated, cohesive and streamlined in order for more Americans to receive the preventive healthcare services they need (p. 18).

Barriers to receiving preventive healthcare services are identified in the National Prevention Strategy (2011) as “logistical, financial, cultural, and health literacy” issues for people the nation (p. 18). While the ACA has removed the cost for many of the preventive care screenings, such as mammograms, colonoscopies, immunizations and behavioral health screenings (Koh & Sebelius, 2010), barriers to receiving preventive care still exist. For example, Khoong, Gibbert, Garbutt, Sumner, and Brownson (2014) identified barriers to preventive care as beliefs about physicians, “disagreement with [preventive care] guidelines, resistance to behavior change, low self-efficacy, and low [health] outcome expectancy” (p. 8).

Through the implementation of the ACA and the National Prevention Strategy, the United States is currently experiencing a paradigm shift in the way healthcare is viewed and

delivered throughout the nation. Although change is occurring, the measurement and assessment of healthcare programs, or community or self-care programs targeting chronic disease remains difficult (Ruiz, Brady, Glasgow, Birkel, & Spafford, 2014). As Harris and Wallace (2012) noted, managing chronic disease in the United States is complicated because treatment measures are not “concordant for a given illness. Some illnesses, such as diabetes, have a great effect on care, while others, such as arthritis, have their greatest effect on mobility, employment, and economic measures” (p. 1).

### ***Self-Managing Chronic Disease***

In addition, the literature shows chronic disease in the U.S. is not "distributed equitably" (Bauer et al., 2014, p. 46) and factors such as socioeconomic status, location, education and race have an impact on health and health outcomes (Braveman, Kumanyika, Fielding, LaVeist, Borresll, Manderscheid, & Troutman, 2011). Effective chronic disease management needs to be accessible, applicable and achievable for all Americans, regardless of socioeconomic status, demographics, race or education level. Hence, low-cost and effective options for chronic disease management are needed, options that capture all Americans, despite their different needs, access, understanding and motivations for managing their illnesses.

In an effort to educate more Americans about the burden of chronic diseases, community-based education sessions to help people learn techniques for the prevention and self-management of chronic disease are becoming more prevalent. A study by Jaglal, Guilcher, Hawker, Lou, Salbach, Manno and Zwarenstein (2014) examined self-management chronic disease programs designed to engage patients to become invested participants in their care. Self-management chronic disease programs promote strategies for self-care so participants may not have to utilize healthcare resources as often (e.g. doctor visits, emergency room visits, etc.). In turn, these

strategies would potentially contribute to a decrease in the overall yearly expenditures on chronic disease related complications. The authors examined data from 104 disease management programs in rural Canada. The results indicated no change in healthcare utilization before and after participating in a chronic disease management program. However, for participants less than 65 years old, physician visits increased by 35% for 12 months following the completion of a chronic disease program, and following the completion of a chronic disease program, hospital emergency department visits decreased for participants aged 66 and older.

Towne, Smith, Ahn, and Ory (2015) addressed sociodemographic factors in rural residents who participated in a Chronic Disease Self-Management Education (CDSME) program and examined the extent to which participants used the workshops if they had limited access to healthcare services. The study used data collected from the first 100,000 adult participants who attended CDSME programs across 45 states, the District of Columbia and Puerto Rico. Twenty-four percent of the participants lived in rural communities; 42% were minorities who were recruited primarily from urban areas. The age of participants was high in both the urban and rural demographics, age 66 for rural participants and age 67 for urban participants. The study showed chronic disease was more prevalent in rural participants (an average of 2.6 chronic conditions in rural residents versus 2.4 chronic conditions in urban participants). The success rate of CDSME completion for rural participants was slightly higher than their urban counterparts at 78% to 77%. Factors inhibiting success included being male (92%) or residing in a primary healthcare shortage area (93%).

Rosland, Heisler, Janevic, Connell, Langa, Kerr, and Piette (2013) found family members or friends are an effective resource to help create a supportive network for chronically-ill adults and potentially bridge “the gap between what chronically-ill adults need and what

health systems can provide” (p. 2). They note family members and friends can help chronically-ill adults by being involved in medication adherence and attending doctor visits, both of which increases overall self-management of chronic conditions and potentially reduces hospitalizations, increases communication with healthcare providers, and increases overall satisfaction with medical care and treatment plans (p. 2).

The authors surveyed 1,722 adults in the United States; 47% were men and the average age was 48. The survey asked participants to identify their social networks and whom they had contact with over a month’s time. The respondents were then asked which of their contacts had been diagnosed with a chronic condition by a healthcare professional. Respondents were asked what involvement they had in the identified individuals’ chronic disease care or health processes. Next, respondents were asked how willing they would be to help or support the identified individuals with their chronic diseases, which included willingness to perform specific tasks and/or identify potential barriers to helping with chronic disease management (p. 3).

The results of the survey showed 64% of respondents acknowledged they were “potential disease management supporters for one or more chronically-ill adults” (p. 4). Women were more likely than men to provide support, people over the age of 50 were more likely to provide support, and people in rural areas were more likely to provide support (p. 4). Eighty-three percent of respondents stated they were willing to provide support, and 51% of the willing supporters said they would accompany chronically ill family members or friends to a doctor’s visit or help them with their medication adherence, or to remember a medical appointment (p. 4-5). Potential barriers to providing support were cited as lack of information, not knowing how to help family members or friends make behavioral changes, and not knowing what questions to ask at a doctor’s visit (p. 6). The authors contended support from family or friends is a

potentially effective resource for helping chronically ill adults self-manage their care. They suggested education classes to assist family members on how to support and care for chronically ill adults is an area for further study (p. 6).

### **Rural Residents and Health Disparities**

The ACA called for healthcare reform in several key area, including a focus on patient and community health. While the promotion of population health is an identified target in the ACA, these changes are difficult to initiate, especially in rural areas. Rural residents are often older, have lower socioeconomic status, face barriers to accessing healthcare, are often underinsured or uninsured, and are more likely to have at least one chronic disease compared to residents living in urban areas (Teufel, Goffinet, Land, & Thorne, 2014; American Hospital Association, 2011; Murimi & Harpel, 2010). As the American Hospital Association (2011) noted, the aforementioned demographic factors often impede rural Americans from “seeking care, which aggravates health problems and leads to more expensive interventions upon receiving care” (p. 2).

The commonplace of chronic disease in rural areas is well-documented, and approximately 60 million people in the United States live in rural areas (U.S. Department of Agriculture, n.d.). Data shows rural residents have limited access to health resources where chronic conditions are prevalent (Missouri Hospital Association, 2013; Logan, Guo, Dodd, Muller & Riley, 2013). The literature pointed to several reasons for high chronic disease prevalence in rural residents, including limited access to quality healthcare, limited education or understanding of chronic conditions, limited financial resources to promote self-management of chronic conditions, and limited support in managing chronic conditions (American Hospital Association, 2011; Mead et al., 2010; Clark et al., 2009).

Gessert, Waring, Bailey-Davis, Conway, Roberts, and VanWormer (2015) suggested more research is needed on how rural and urban residents view healthcare to ensure patient-centered care is truly targeted to the specific beliefs and needs of people living in a certain demographic areas. In a systematic literature review, the authors examined 34 articles related to “a rural definition of health” (p. 1). Of the 125 articles initially identified, only 34 met the criteria, which included original research written in English and published within the last 40 years, research that identified a rural definition of health, and research conducted in rural areas of the United States, Canada and Australia. While the authors noted the study was limited because very few articles specifically identified differences in rural and urban ideas of health, significant findings indicated rural populations tend to recognize good health as “being able to work,” being able to have meaningful social relationships and being able to maintain independence (p. 3). The authors suggested further research is needed to see how rural and urban populations view health in order to target areas to improve patient compliance, which is the extent to which a patient follows medical advice, and patient engagement, which is a patient’s ability, knowledge or confidence to self-manage health and participate in healthy living activities.

Bolin, Bellamy, Ferdinand, Vuong, Kash, Schulze, and Helduser (2015) identified the role of Rural Healthy People 2020, an initiative funded through the Texas A&M Health Science Center. Rural Healthy People 2020 works in tandem with Healthy People 2020, a subsidiary of the U.S. Department of Health and Human Services by allowing rural residents and key rural stakeholders to identify and measure the health concerns and priorities of the United States' rural population. In a survey completed by 1,214 rural participants, the authors reported few health concerns and issues have changed for rural residents over the past 10 years. Common concerns



still focused on access to emergency and primary care, and financial concerns, such as adequate health insurance.

### ***Healthcare Avoidance***

Eberhardt and Pamuk (2004) studied health in conjunction with the importance of residential place, and found the greatest health disparities were in the most urban and most rural areas. The authors noted rural residents were the most disadvantaged in the following areas: premature mortality; higher death rates from accidental injuries; suicides; and chronic diseases, such as chronic obstructive pulmonary disease (COPD), cardiovascular disease and cancer. Factors contributing to higher risks of these disadvantages were based on demographic and socioeconomic issues common in rural areas, including limited education, low income and lack of health insurance.

Logan et al. (2013) studied the commonness of four main types of chronic disease, including diabetes, cardiovascular disease, cancer and arthritis. The study concentrated on six rural counties in Florida and was conducted from November 2009 to March 2010. Professional interviewers completed the study, and 2,605 interviews were conducted over four months. Participants who identified themselves as White or Black were included in the study, which resulted in a sample size of 2,381 adults, aged 25 and older. Participants were surveyed on tobacco use, depression, financial security, education level and health literacy. The study found lower financial security was connected to cardiovascular disease, diabetes and arthritis; depression was more common with cardiovascular disease, diabetes and arthritis; tobacco use was connected to cancer and cardiovascular disease, both for current and former smokers; diabetes was most prevalent in Blacks and women; women with a higher level of education were less likely to report diabetes as compared to women with lower levels of education; and overall,

lower financial security was correlated with a higher reported instance of chronic disease (p. 5). The authors concluded information related to chronic disease needs to address "behaviors and other pertinent demographic and geographic factors" (p. 7) in order to bridge the gap between rural and urban health disparities.

Healthcare avoidance and lack of patient engagement, which is a patient's ability, knowledge or confidence to self-manage health and participate in healthy living activities, are two other characteristics prominent in the rural population. Murimi and Harpel (2010) examined the individual and social factors that impeded 38 adult residents living in a rural county in Louisiana from seeking preventive care through a rural health outreach program. The authors research questions focused on the motivations, barriers and potential changes needed to increase participation in preventive care (p. 275). The participants were interviewed using open-ended questions in a focus group setting to determine motivating and inhibiting factors to preventive care participation. The study's identified barriers included lack of time, low priority, fear of the unknown, and lack of support and companionship. Interestingly, the participants cited the availability of free food as a strong motivator to participating in the rural health outreach program (p. 277).

Campbell et al. (2014) studied the correlation between income and the willingness to adhere to healthy behavior changes in 1,849 participants in Western Canada who had some type of chronic cardiovascular disease. The study's purpose was to identify what factors preclude low-income individuals from participating or adhering to positive health behavior changes, including health recommendations and preventive care. The study showed low-income participants were more likely to cite barriers as lack of access and limited funding as two reasons they did not adhere to positive health behavior changes.

Spleen, Lengerich, Camacho, and Vanderpool (2013) expanded upon previous research establishing that specific groups tend to avoid healthcare due to an array of factors, including socioeconomic status, personal beliefs, healthcare access, financial concerns and past situations involving unfavorable experiences with physicians. Using the 2008 Health Information Trends Survey (HINTS), the authors examined 6,714 surveys and identified a significance ( $p < .05$ ) of healthcare avoidance in rural residents; males; younger ages (18-34 years); the uninsured; a lack of confidence in personal healthcare; not having a primary care provider; not trusting physicians; and a lack of developing a relationship with physicians. Similarly, Ranson, Terry, Glenister, Adam and Wright (2016) examined disparities in rural healthcare and asserted the future of health must focus on self-care measures and address the underlying causes of fatalism and/or the acceptance of rural-urban health disparities by rural populations.

Young et al. (2013) acknowledged patient engagement, which is a patient's ability, knowledge and/or confidence to effectively manage health and participate in health-promoting activities, is a critical component of chronic disease management. The authors' study examined patients with asthma who lived in a rural area. The study used a cross-sectional telephone survey with 98 participants to identify what patients perceived as motivating and/or inhibiting factors to self-care. The results of the study indicated 50% of the participants were highly engaged in their healthcare and the promotion of self-care for their asthma at home. These patients were more likely to comply with medication and treatment guidelines than their less-engaged counterparts. The authors indicated future studies should target the rural chronic disease patients who exhibited lower levels of patient engagement and motivation to help identify areas to entice them to become more proactive.

## **Self and Preventive Care**

Interventions targeting self-management of chronic conditions is documented as an important component to combating the chronic disease epidemic (World Health Organization, 2013). Self-care is cited in the literature as a low-cost mechanism to improve chronic disease health outcomes by increasing personal confidence, improving symptom management and reducing hospitalizations (Riegel, Dickson, & Faulkner, 2016; Davidson, Inglis, & Newton, 2013; Vellone, Pancani, Greco, Steca, & Riegel, 2016).

While self-care has been cited as a necessary component to living with a chronic disease, the term itself is difficult to define, as noted in Disler, Gallagher, and Davidson (2012). They asserted self-management “is a complex construct and influenced by a range of factors. Understanding the diverse factors contributing to self-management is important in developing tailored and targeted interventions to self-care” (p. 240). The authors argued self-management is more than just day-to-day tasks and following medication regimens and medical advice, because while “these definitions cover important aspects of self-management, [they] fail to encompass the complex psychological, social, existential and physical determinants” which chronic disease patients live with on a daily basis (p. 240).

Riegel et al. (2016) described self-care as "a naturalistic decision-making process that influences actions that maintain physiologic stability, facilitate the perception of symptoms, and direct the management of those symptoms (p. 226). The authors asserted self-care involves three processes, including maintenance, which involves following health and wellness recommendations, (e.g. taking medications), symptom perception, which involves recognizing and acknowledging symptoms; and management, which involves responding to symptoms when they occur (p. 227).

Riegel, Jaarsma, and Stromberg (2012) identified self-care methods as a needed tool to manage chronic conditions. The authors introduced three specific and interrelated areas of self-care for patients living with chronic disease to help them maintain their quality of life and manage their disease. Through these "health promoting practices" (p. 194) the authors identified areas for implementing a self-care plan, which included self-care maintenance, self-care monitoring and self-care management.

Sayers, Riegel, Pawlowski, Coyne, and Samaha (2008) studied social support and its influence on self-care. They recruited "74 patients with heart failure from a cardiology clinic in a Veterans Affairs Medical Center and a university-affiliated hospital" to determine whether social support affected self-care in areas of medication compliance, diet restrictions and other heart failure monitoring components (e.g. weight maintenance). The authors found without social support, self-care compliance, or the extent to which patients follow medical advice to care for themselves, was very low, across all tested areas. Social support did improve daily self-care adherence, specifically in areas of medication compliance and weight management.

Similarly, Cene, et al (2015) examined self-care in patients who had a family member attend medical appointments with them. The authors recruited 150 heart failure patients from an internal medicine or cardiology clinic from a university hospital. The participants were asked survey questions about self-care maintenance and how many times the patient had family members attend doctor appointments, or how many times a family member had contacted the participant's doctor about his or her care, either by phone or email. The study also examined the participants' satisfaction with their healthcare provider's communication. The results identified family accompaniment to healthcare visits increased participants' self-care management scores, but family accompaniment did not influence perceptions on provider communication.

As Gardner (2014) noted, information access alone does not change patient behavior; she further noted even if patients have increased access to quality healthcare services, treatments and education, an increased percentage of positive health changes will not occur in communities if there are not opportunities provided by healthcare organizations for patient and provider collaboration. Patient engagement, which is a patient's ability, knowledge and/or confidence to effectively self-manage health and participate in health-promoting activities, is also cited in the literature as a vital component to effective self-care (Simmons, Woelver, Bechard, & Snyderman, 2014; Siabaini, Leeder, & Davidson, 2013).

Further, even if some patients understand their chronic conditions and the need to improve certain risk factors, sustained change is unlikely without support. Khare, Koch, Zimmermann, Moehring, and Geller (2014) followed 162 women with cardiovascular disease living in rural Illinois who participated in behavior modification interventions for one-hour sessions over 12 weeks. All 162 women completed the program with noted improvements in their diet and exercise programs, but these changes were not sustained over a year. The authors suggested a follow-up plan may help participants maintain prolonged health behavior changes.

Simmons et al. (2014) asserted patient engagement is an essential component to healthcare outcomes. The authors defined patient engagement as a three-part model, which includes, "(1) recognizing and understanding the importance of taking an active role in one's health and health care; (2) having the knowledge, skills, and confidence to manage health; and (3) using knowledge, skills and confidence to engage in health-promoting behaviors to obtain the greatest benefit" (p. 2). The authors reviewed the existing literature on the correlation between patient engagement and chronic disease outcomes to determine if patient engagement should be considered a risk factor when constructing patient chronic disease management models. The

authors reviewed clinical trials conducted from January 1993 through December 2012 using Medline, Embase and Cochran databases. The authors reviewed 543 abstracts and selected 10 that met pre-study criteria. Nine studies indicated health improvements when patients were engaged in their care; five studies indicated a reduction in clinical markers of disease when patients were engaged; and all studies showed improvements in health status, based on patient self-reporting. The authors concluded patient engagement should be part of a chronic disease maintenance plan, as it helps patients in their self-management processes.

Siabaini et al. (2013) examined the barriers and facilitators to self-care in patients with chronic heart failure. Patients with chronic heart failure who lack the ability to perform self-care measures at home are at an increased risk for recurrent hospitalizations and an overall poor quality of life. The authors' purpose of the study was to address the question, "What are the barriers and facilitators to self-care among patients with CHF" (p. 1). The study examined peer reviewed articles from 1995 to 2012 that included at least one instance of self-care and its impact on CHF patients, and 23 articles met the criteria. The authors determined the symptoms of CHF, the self-care process, personal factors and environmental factors affected the ability of CHF patients to perform self-care at home. The authors' recommendations for future studies included examining how socioeconomic status and education level affects the self-care process.

Self-care responsibility is another debated issue in the literature. Although patients are responsible for their own care, providing them with chronic disease information alone does not change behaviors, nor does information alone account for patients' past experiences and life situations (Gardner 2014; Auduly, Asplund, & Norbergh, 2010). Chronic disease progression also needs to be considered, because over time patients' needs may change as their disease progresses (van Houtum, Rijken, Heijmans, & Groenewegen, 2013). Thus, the literature

suggested there should be a shared, ongoing responsibility for self-care between providers, healthcare workers and patients.

Peek, Drum, and Cooper (2014) investigated the role of shared decision making (SDM) as a tool for patients living with chronic disease to incur optimal health outcomes. The authors define SDM as having "three domains: information sharing between patients and physicians, deliberation about pros and cons of treatment options, and decision making about a treatment plan that is agreed upon by both the patient and physician" (p. 2). The authors used a cross-sectional study of patients enrolled in a randomized clinical trial. The 273 patients included in the study were adults, aged 18 and older, who had hypertension and received healthcare from a community health clinic in Baltimore, Maryland. The study used patient surveys to collect data, and the results indicated patients with who had greater chronic disease burden and diseases requiring self-management, as well as patients who were in poor health, were more likely to participate in information sharing with their physicians and decision making about their treatment plans.

Audulv et al. (2010) asserted self-management is not possible until the individual acknowledges the problem and is willing to take responsibility for his/her disease (p. 95). Their study included narrative interviews with 26 adult participants who had been diagnosed with a chronic disease for an average of 16 years. After analyzing the results, the authors discovered the participants viewed responsibility differently, with 12 participants viewing responsibility internally, eight participants viewing responsibility externally, and six participants viewing responsibility both internally and externally (p. 96). The participants who viewed responsibility internally were the ones who took an active role in their healthcare and outcomes. The participants who viewed responsibility externally viewed their health and outcomes as beyond



their control; they felt they had a “limited influence on the disease prognosis” (p. 97). The participants who viewed responsibility externally were also less likely to question their healthcare providers’ recommendations (p. 98). The authors acknowledge the participants’ views of responsibility were dependent on their illness, experience and life events (p. 99).

Van Houtum et al. (2013) examined the self-management support needs of patients with chronic illness over time. They asserted chronic disease education/management programs are problematic because patients have different needs, and these needs morph over time (p. 626). The authors used a survey about overall health and the need for self-care support (p. 627), and 1,688 participants, with an average age of 61 years and a chronic condition, completed the survey. The authors found patients who perceived their illnesses to be “stable or episodic” had been diagnosed more recently than patients who viewed their illnesses as “stable or deteriorating” (p. 630). Patients who perceived their health as stable had the highest overall health scores, while patients who viewed their conditions as deteriorating had the lower overall health scores. Additionally, patients who had been ill the longest period of time had the lowest overall health scores (p. 630). The authors discovered overall “older people, women, lower educated people, people who live alone and people who have more than one chronic disease had higher support needs” (p. 630). Also, if a patient’s health had deteriorated over the last year, his/her support needs were also elevated (p. 630). The authors asserted patients need support over the course of their chronic illnesses, as conditions change over time. Further, the amount of support needed is dependent on external factors as well as the type of chronic disease (p. 631).

### **Heuristic Elicitation Methodology (HEM)**

The Heuristic Elicitation Methodology (HEM) is an ethnographic research method derived from social science in which “the needs, goals, and values of a community are studied in

such a way as to provide information to planners to use in designing programs and projects” (Nardi & Harding, 1978). Ethnography seeks to examine human behavior and the ways people make meaning of their worlds, environments and lives, and ethnography asserts the study of a group “provides understanding of a larger issue” (Creswell, 2015, p. 466). Ethnography also recognizes people’s “lives are highly variable and locally specific” (LeCompte & Schensul, 1999). In addition to expanding on its ethnographic origins, the HEM also helps ensure the development of a new policy, project or program is “culturally appropriate” or “culturally relevant” (Harding & Livesay, 1984).

### ***The Philosophy of HEM***

The philosophical basis of HEM is derived from interpretivism. Interpretivism, or social constructivism, is a philosophy in which people seek meaning from their lives and surroundings. In interpretivism, people strive to create a sense of purpose in their experiences, and these meanings are often complex, “varied and multiple” (Creswell, 2013, p. 24).

The HEM is created to draw out and examine cultural themes shared by a group (Creswell, 2013; Spradley, 1979). Creswell (2015) described a cultural-sharing group as “two or more individuals who have shared behaviors, beliefs, and language” (p. 472). A cultural-sharing group has shared cultural themes that often are understood, or implied, rather than spoken, even though the shared cultural principle is used “to organize their behavior and interpret knowledge” (Spradley, 1979, p. 188).

The HEM, therefore, is a strategy designed to help examine and extract these cultural themes and create significance from them. The HEM assumes a cultural-sharing group uniquely responds to the environments in which they live and work and examines the relationships between a group’s language, perceptions and reasonings (Harding & Livesay, 1984). The HEM

uses methods “specifically designed to elicit the respondents’ own categories in their own language” (Harding & Livesay, 1984, p. 75).

### ***The Methodology of HEM***

The HEM combines qualitative and quantitative methods and incorporates three main phases, or procedures: the domain definition, the beliefs matrix and the preference ranking (Nardi & Harding, 1978; Harding & Livesay, 1984; Kupritz, 1996).

The HEM uses elicitation techniques where the researcher asks participants a “series of interlinked questions in which responses to one question determine the form of subsequent questions” (Nardi & Harding, 1978, p. 39).

**Figure 1.** Heuristic Elicitation Methodology

<b>Heuristic Elicitation Methodology</b>			
	<u>Stage I</u>	<u>Stage II</u>	
Instrument	Domain Definition	Beliefs Elicitation	Preference Rankings
Type of Data	Qualitative	Quantitative	Quantitative
Brief Description	Open-ended interviews in which respondents answer a series of interlinked questions that are recorded verbatim to preserve the language and conceptualizations of the respondents.	Structured interviews in which respondents answer yes or no to questions reflecting aspects of the problem of interest expressed in the concept elicitation.	Structured interviews in which respondents rank order, based on their own preferences, items and attributes in the domain of interest.
Type of Analysis	Content Analysis	Statistical techniques from frequencies and distributions to multi-dimensional scaling and hierarchical clustering (the latter are optional).	Mean rankings, tests of significance for subgroup differences.

### ***The Domain Definition***

The Domain Definition is the first phase of the HEM (and the only phase utilized in the present study), which incorporates structured interviews designed to exhaust all possible answers from the study's participants (Harding & Livesay, 1984; Spradley, 1979). The researcher asks a series of interlinked questions in order to elicit all possible answers from the respondents. The first group of questions are used to establish the domain characteristics, or cover terms, while the second set of questions, or "probe" questions, are designed to help probe the respondent to think of any other possible answers, which "determine the attributes of each item in the domain" (Nardi & Harding, 1978, p. 39). The responses to these questions are recorded verbatim in order to preserve the language of the group being studied (Nardi & Harding, 1978; Harding & Livesay, 1984).

Nardi and Harding (1978) gave an example of the domain definition with the following questions:

Q1. What are the different places where people get birth control methods? Probe-What other places are there where people get birth control methods?

Q2. What methods do people get from "X"? (X refers to each source of methods elicited in the previous question.) Probe-What other methods do people get from "X"?

The respondents' answers to the first question are then plugged into the following questions in order to exhaust the domain (Harding & Livesay, 1984, p. 77). The domain is exhausted only when the respondent can no longer think of any other answers (Nardi & Harding, 1978, p. 40), and the goal of the domain definition "is to elicit a broad, if not the complete, range of items in the domain" (Harding & Livesay, 1984, p. 77).

### ***The Beliefs Elicitation***

The second phase of the HEM is the beliefs elicitation. The beliefs elicitation uses the responses elicited from the domain definition and is designed to further identify the beliefs, attitudes and perceptions of the respondents and “to determine interrelationships among them” (Kupritz, 1996; Harding & Livesay, 1984). A structured questionnaire is used during this phase, and the questions are developed from the original respondents’ answers, thus continuing to preserve the language used by the culture-sharing group (Kupritz, 1996; Nardi & Harding, 1978).

Kupritz (1996) explained: “The Matrix consists of a set of row by column categories. The categories cross-relate items and attributes via a question that can be responded by a ‘yes’ or ‘no.’ The respondent can be queried on all possible permutations of row by column categories in a relatively short period of time, utilizing the matrix format” (p. 318). The responses are analyzed by adding all of the “yes” responses from each of the matrix cells (Nardi & Harding, 1978, p. 40), and the matrix data allow for a large amount of information to be accumulated relatively quickly. As Nardi and Harding (1978) noted, studying the “frequencies and perhaps certain simple correlational analyses offer the researcher sufficient information upon which to base judgments concerning the design or modification of a program or project” (p. 40).

### ***Preference Rankings***

The final phase of the HEM is the preference rankings, which is designed to determine the respondents’ personal preferences from the characteristics identified in the domain definition. The respondents are asked “to rank order all items from most to least preferred” (Harding & Livesay, 1984, p. 82). The preference rankings are ideal for determining which attributes a targeted population finds favorable, as well as which attributes the same population finds unfavorable. The information gathered from the preference rankings is significant, especially

when determining a new policy or program (Kupritz, 1996; Harding & Livesay, 1984; Nardi & Harding, 1978).

## **Summary**

In 2010, the implementation of the ACA called for drastic reform to the United States healthcare system by targeting the availability of health insurance, the access to health services, the reduction of healthcare-associated costs, and the importance of prevention. While many Americans have benefited from the health reform measures created by the ACA, there is still work to be done to ensure all Americans have the access, tools and resources needed to achieve good health. In addition, research needs to be done on what motivates or entices people to take advantage of available resources.

Chronic disease is responsible for much of the burden on the U.S. health system and accounts for ongoing health problems, disability and healthcare costs, as well as the deaths of 70% of the population (Torres et al., 2017; Bauer et al., 2014; National Prevention Strategy, 2014; Harris & Wallace, 2012; Centers for Disease Control and Prevention, 2009). In rural areas, chronic disease is further exacerbated by factors such as lower socioeconomic status and education, lack of insurance and limited healthcare accessibility. People living in rural areas are especially vulnerable to their chronic diseases, as they may not understand how to go about managing their conditions, and thus delay seeking care (Murimi & Harpel, 2010; Clark et al., 2009). The literature suggested self-care and/or self-management of chronic disease is evidenced-based to produce better outcomes and quality of life for people living with chronic conditions.

While a “one size fits all” approach to self-care is not conducive to chronic disease as a whole, the benefits to taking control of one’s own health is empowering and productive

(Trappenburg, Jaarsma, Os-Medendorp, Kort, Hoes, & Schuurmans, 2013, p. 134). Hence, continued research on applying and transferring accessible self-management techniques to patients is needed to ensure Americans living with chronic conditions receive the skills and resources required to become proactive participants in their care.

## **Chapter 3**

### **Methodology**

#### **Overview**

The purpose of this ethnographic study was to identify what factors motivate and challenge rural residents living with a chronic disease in performing and/or completing self-care practices at home. The current chapter addresses the study's proposed methodology, including participants; research design; data collection instrumentation and methodology; and data analysis.

#### **Rationale for Ethnographic Study**

The present study used an ethnographic qualitative design. According to Creswell (2013), ethnographic research "describes and interprets the shared and learned patterns of values, behaviors, beliefs, and language of a culture-sharing group" (p. 90). As a research process, the ethnographic researcher immerses him/herself in the participants' daily lives by observing and interviewing the group participants to identify the shared language, patterns and beliefs of the group (Creswell, 2013, p. 90).

The present study's research question supported using an ethnographic approach, because it sought to understand the factors that motivated and inhibited chronic disease patients from caring for themselves at home.

#### **Research Setting**

The Missouri Hospital Association (2013) reported 37% of the state is rural (an approximate 2.2 million of the population), and the rural population has more chronic diseases than their urban counterparts. The MHA also listed three areas of chronic disease that are more prevalent in rural Missourians as opposed to urban Missourians. These diseases included chronic



obstructive pulmonary disease, heart disease and hypertension (Missouri Hospital Association, 2013).

The research setting for the study was the Congestive Heart Failure Clinic located at a healthcare facility in Rolla, Missouri. The designated healthcare organization service territory included six rural counties, including Crawford, Dent, Maries, Phelps, Pulaski and Texas. The healthcare organization is one of Missouri's leading regional referral centers and serves over 200,000 residents in south-central Missouri (Phelps County Regional Medical Center Community Benefit Report, 2014). As a safety-net hospital, the organization provides accessible healthcare to people of all ages, regardless of ability to pay. Participants enrolled in the congestive heart failure clinic at the healthcare facility were recruited for the study.

The City of Rolla has the highest population (20,000) of any of the six counties in the healthcare organization's service area. Rolla "has a more urban feel, due primarily to the diversity of the individuals drawn to the Missouri University of Science and Technology (Missouri S&T), which is located there. Missouri S&T is a top-ranked technological research university with more than 7,500 undergraduate and graduate students from 49 states and 50 countries" (South Central Missouri Community Health Center New Access Point Grant Application, 2011, p. 5). Outside of Rolla, the towns and community decrease in population and wealth. Some areas are poverty-stricken, and some residents have to drive 20 miles or more to access any type of services (healthcare, food, etc.) (South Central Missouri Community Health Center New Access Point Grant Application, 2011).

In Phelps County, the percentage of residents living in poverty is 21.6% (United States Census Bureau, 2014). Phelps County is designated as a rural county, because it has a population density of 67.2 people per square mile; this is compared to the state of Missouri, which has a

population density of 86.9 people per square mile (South Central Missouri Community Health Center New Access Point Grant Application, 2011).

There are no public transportation or bus systems available to service residents living in Phelps County or surrounding counties (South Central Missouri Community Health Center New Access Point Grant Application, 2011). Therefore, transportation is a major concern for those individuals who do not own vehicles, and “for rural residents without cars—or the funds to maintain their cars—it is almost impossible to keep a job, shop for affordable groceries, or seek medical care” (South Central Missouri Community Health Center New Access Point Grant Application, 2011, p. 6).

### **Research Sample**

This ethnographic study used purposeful sampling to identify potential participants who were enrolled in the congestive heart failure clinic at a healthcare facility in Rolla, Missouri. Creswell (2013) identified purposeful sampling as a when a researcher "selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study" (p. 156). Congestive heart failure (CHF) was chosen as a research area, because heart disease is the leading cause of death in five of the six counties served by the designated healthcare organization (Phelps County Regional Medical Center Community Health Needs Assessment, 2016).

The researcher contacted the Heart & Vascular Center at the healthcare facility to identify participants who met the research criteria and who were willing to participate. Representatives from the Heart & Vascular Center contacted the participants first to preserve doctor/patient confidentiality, and once the individuals agreed to participate, the researcher was given the patients' contact information.

Participant criteria were as follows:

1. All participants were enrolled in the Congestive Heart Failure Clinic at a designated healthcare facility in Rolla, Missouri.
2. All participants were diagnosed and living with congestive heart failure for at least one year.

The researcher chose a delimitating time frame of one year or more to ensure the participants were familiar and accustomed to the health recommendations and procedures for performing congestive heart failure self-care at home. The sample included 10 participants who verbally agreed to be included in the study. The researcher acknowledges that while all participants were enrolled in the Congestive Heart Failure Clinic, there were differences in the following areas: number of years living with congestive heart failure, age, gender, education, number or visits to the congestive heart failure clinic and socio-economic status.

### **Information Needed to Conduct the Study**

The present ethnographic study focused on the attitudes, beliefs and language of 10 congestive heart failure patients enrolled in a congestive heart failure clinic in Rolla, Missouri. In order to identify the participants' perceptions of the factors that promote and/or inhibit performing self-care at home, the study included one research question to identify trends and shared ideas of the participants. The information needed to answer the research question were determined by four categories:

1. **Contextual.** Information was gathered that addressed where the participants received their healthcare.
2. **Perceptual.** Information was gathered on the participants' perceptions of what does or does not allow them to perform self-care measures at home.

3. **Demographic.** Information was gathered about the participants, including the number of years living with congestive heart failure; age; gender; education level; ethnicity; and socioeconomic status.
4. **Theoretical.** Information was gathered from an ongoing review of the literature to provide the conceptual framework for the study.

### **Research Methodology**

The present ethnographic study examined the shared ideas, beliefs and language of patients living with congestive heart failure in a rural Missouri area to identify what factors motivated and inhibited them from performing self-care measures at home. The researcher interviewed 10 patients living with congestive heart failure, who were also enrolled in a congestive heart failure clinic in Rolla, Missouri. The researcher gathered data using one-on-one interviews with the 10 participants. Interviews lasted anywhere from 20 minutes to an hour and a half and were conducted on site at the healthcare facility or in the participants' homes. Many of the interviews occurred following an appointment with the participants' cardiologist.

The researcher used a hand-held recorder to record the interviews and collected data from observations and note-taking. Following the one-on-one interviews, the transcripts were downloaded to the computer and saved to a flash drive. Interviews were kept confidential by not including any identifying information. Participants were reminded before and after the one-on-one interview that they could withdraw from the study at any time.

The study used the elicitation phase of the Heuristic Elicitation Methodology (HEM) as described in Nardi and Harding (1978). The elicitation phase of the HEM was used to ask participants a series of interlinked questions in order to determine how they perceived their ability to perform self-care at home.

## Data Collection

The HEM is an ethnographic method that seeks to preserve the intrinsic language and beliefs of a culture-sharing group in order to decrease the possibility of overlooking any characteristics within the area, or domain, being investigated (Harding & Livesay, 1984). Nardi and Harding (1978) described the domain definition, the first phase of the HEM in the following way:

The domain definition is a technique in which a relatively small number of respondents are systematically questioned about a particular area of interest (or domain) in order to provide a basis for further investigation of the various elements in that domain...The questioning helps the investigator discover as many different items in the domain of interest (for example, kinds of housing) and their attributes (i.e., dimensions, features, traits, characteristics,) as possible (p.39).

Using the elicitation phase of the HEM, the researcher conducted one-on-one structured interviews with participants to identify the domain characteristics associated with living with congestive heart failure. The researcher asked the participants six interlinked questions to preserve the language of the culture-sharing group. The participants' responses to the first questions were used to form the subsequent (probe) questions in order to exhaust all possible answers. The following questions are examples of what the researcher asked the participants:

1. Q: What are the different kinds of things that you do, or try to do, to take care of your congestive heart failure (CHF) at home? Probe: What other things do you do, or try to do, to take care of your CHF at home? [answers = "x"]
2. Q: For/When "x," what conditions, factors, tools or situations make it easier to conduct "x"? [answers = "y"] Probe: What else makes it easier to conduct "x," other than "y"?

3. Q: For/When "x," what conditions, factors, tools or situations make it difficult to conduct "x"? [answers = "y"] Probe: What else makes it difficult to conduct "x," other than "y"?
4. Q: What conditions, factors, tools or situations have not allowed you to do "x"? [answers = "y"] Probe: What else has not allowed you to do "x," other than "y"?
5. Q: What conditions, factors, tools or situations would make the ideal situation for you to do "x"? [answers = "y"] Probe: What other conditions, factors, tools or situations would make the ideal situation for you to do "x," other than "y"?
6. Q: What conditions, factors, tools or situations would the ideal situation not have, or avoid, in order for you to do "x"? [answers = "y"] Probe: What other conditions, factors or situations would the ideal situation not have, or avoid, in order for you to do "x," other than "y"?

### **Data Analysis**

Following the one-on-one interviews, all participant interviews were transcribed, and the content was analyzed by the researcher and a member of the study's committee. The participants' responses were examined to identify/extract themes, patterns and relationships using Spradley's domain analysis methods (Spradley, 1979). The transcribed interviews were examined one-by-one, and all related cover terms and included terms were highlighted. Once all cover terms and included terms were identified, the researcher and committee member grouped the cover terms and included terms according to their semantic relationships. For example, included terms pertaining to diet strategies, needs, problems and hindrances were grouped together; included terms relating to exercise strategies, needs, problems and hindrances were grouped together, and so on.

## **IRB Approval**

Prior to beginning research for this study, the researcher requested permission from the Institutional Review Board (IRB) at the University of Arkansas. The researcher requested an expedited level of review from the IRB due to the following components: all participants were adults and over the age of 18, the participants were not anonymous, and the participants' age and gender were included. In addition, the research involved no more than a minimal risk, and prisoners and pregnant women were not included in the study.

## **Trustworthiness of Data**

The domain or elicitation process of the HEM requires the use of probe questions to exhaust all possible responses from participants in order to preserve the language of a culture-sharing group (Nardi & Harding, 1978). The probe questions ensured the researcher did not neglect to include aspects of the domain, as the participants supplied the responses (Spradley, 1979).

The researcher also used field notes taken during the one-on-one interviews and peer review. The researcher worked with a member of the study's committee to examine the questions, research methodology, extract themes and determine a consensus when analyzing the data. The researcher and the committee member kept a written account of the data analysis meeting and process (Creswell, 2013).

## **Summary**

The purpose of the present ethnographic study was to identify what factors motivate and impede rural residents living with a chronic disease in completing self-care practices at home. Ten patients living with congestive heart failure were interviewed one-on-one by the researcher.

These 10 individuals were also enrolled in a congestive heart failure clinic at a healthcare facility in Rolla, Missouri.

The study incorporated the domain or elicitation phase of the Heuristic Elicitation Methodology (HEM) and was used to ask participants interrelated and probe questions in order to extract all possible answers about how they perceived their ability to perform self-care at home. (Nardi & Harding, 1978).

The HEM is an ethnographic research method, which preserves the language of a culture-sharing group (Nadi & Harding, 1978; Harding & Livesay, 1984). The interlinked questions and probe questions ensured the researcher did not leave out any possible answers. The researcher also asked a member of the study's committee to peer-review the transcribed information, extract themes, answer questions and provide feedback.



## **Chapter 4**

### **Results**

#### **Overview**

The purpose of this ethnographic study was to identify what factors motivate and challenge rural residents living with a chronic disease in performing and/or completing self-care practices at home. The researcher felt understanding the self-care perceptions of rural residents living with congestive heart failure may better help educators and hospital administrators to develop/refine rural chronic disease self-management programs. This chapter presents the findings following 10 one-on-one interviews with rural, congestive heart failure patients.

#### **Research Question**

The study addressed the following research question:

1. How do congestive heart failure patients living in a rural area perceive their ability to perform self-care measures at home?

#### **Participant Demographics**

A total of 10 individuals were invited to participate in this study. Participants were selected using purposeful sampling, were enrolled in a congestive heart failure clinic at a healthcare facility in Rolla, Missouri, and the participants had been living with congestive heart failure for one year or more. Of the 10 participants who agreed to be interviewed for the study, only eight completed a basic demographics survey, which resulted in an 80% response rate. The participants were primarily female 75% (n=6), with males representing only 25% (n=2). The age of participants was primarily 65 or older, or 62.5%. Participants aged 50-64 were 25%, and participants aged 30-49 were 12.5%.

There were no college graduates in the sample. 62.5% were high school/high school equivalent graduates, 25% had trade/technical school training, and only 12.5% (n=1) had some

college. All participants (n=8) identified with a religious practice, 50% as Protestant, 25% as Roman Catholic, and 25% (n=2) as Other (listed in both instances as Baptist). 87.5% of the responses identified their race as White, and 12.5% (n=1) reported ethnicity as American Indian.

Annual income levels were as follows: 25% (n=2) identified with less than \$20,000 per year; 37.5% (n=3) identified with \$20,000-\$34,999 per year; 12.5% (n=1) identified with \$50,000-\$74,000 per year; and 25% (n=2) identified with \$75,000-\$99,999 per year. Based on this information, 62.5% (n=5) of the participants identified as having an annual income of \$34,999 or less, which is 200% or below the federal poverty level (FPL).

Three-fourths (75%) of the respondents were retired, and 25% of the respondents were not employed. Half (50%) of the respondents claimed two as the number of people in their household, with 12.5% claiming one, 12.5% claiming three, 12.5% claiming seven, and 12.5% not responding.

The percentage of participants who had no children under the age of 18 living in their households was 87.5%. Marital status was split down the middle, with 50% responding as married and 50% responding as divorced. Household computer access was identified as 62.5% (n=5), while 25% did not have access to a computer, and 12.5% did not respond. Similarly, 50% (n=4) knew how to use a computer, 37.5% (n=3) did not know how to use a computer, and 12.5% did not respond.

### **Congestive Heart Failure and Best Practices**

Heart failure is a leading cause of death in the United States and is responsible for billions of healthcare dollars spent each year (Centers for Disease Control and Prevention, 2016; Siabani et al., 2013). In addition, “about half of people who develop heart failure die within five years of diagnosis” (Centers for Disease Control and Prevention, 2016, p. 1). Self-care practices for heart

failure “can be complex, requiring continuous attention to diet, medication, and symptoms and multiple visits with healthcare providers” (Kennedy, Jaligam, Conish, Johnson, Melancon, & Katzmarzyk, 2017, p. 93).

Best practices for self-managing heart failure include the following: maintaining a heart-healthy diet low in sodium, eating fewer salty or sodium-filled foods, losing weight (if needed), tracking daily fluid intake, taking prescribed medications daily, taking blood pressure daily, getting plenty of rest, weighing daily to check for fluid weight gain, exercising, and limiting alcohol and caffeine (American Heart Association, 2015).

### **Congestive Heart Failure Management Activities**

Through the HEM elicitation (domain) analysis, participants identified the following cover terms, which are the names of things within a category of cultural knowledge (Spradley, 1979), during the domain definition, which is the first phase of the HEM where participants are asked a series of interlinked questions and probe questions in order to elicit all possible answers within a domain (Nardi & Harding, 1978). In the present study, the following cover terms were identified: congestive heart failure (CHF) management activity; lack of CHF management activity; salt/sodium; diet; fluid; stress; support; medication; blood pressure; sleep/rest; weight; exercise; CHF overall management activity; and the outliers of staying indoors; staying out of the cold; moving from different state; knowing limitations; and reading a pacemaker.

CHF management strategies, needs, problems and hindrances were determined according to the interview questions and probe questions. Examples are as follows:

1. Q: What are the different kinds of things that you do, or try to do, to take care of your congestive heart failure (CHF) at home? Probe: What other things do you do, or try to do, to take care of your CHF at home? [answers = "x"]

2. Q: For/When "x," what conditions, factors, tools or situations make it easier to conduct "x"? [answers = "y"] Probe: What else makes it easier to conduct "x," other than "y"? [**Answers = strategies**]
3. Q: For/When "x," what conditions, factors, tools or situations make it difficult to conduct "x"? [answers = "y"] Probe: What else makes it difficult to conduct "x," other than "y"? [**Answers = problems**]
4. Q: What conditions, factors, tools or situations have not allowed you to do "x"? [answers = "y"] Probe: What else has not allowed you to do "x," other than "y"? [**Answers = problems**]
5. Q: What conditions, factors, tools or situations would make the ideal situation for you to do "x"? [answers = "y"] Probe: What other conditions, factors, tools or situations would make the ideal situation for you to do "x," other than "y"? [**Answers = needs**]
6. Q: What conditions, factors, tools or situations would the ideal situation not have, or avoid, in order for you to do "x"? [answers = "y"] Probe: What other conditions, factors or situations would the ideal situation not have, or avoid, in order for you to do "x," other than "y"? [**Answers = hindrances**]

### **Salt/Sodium Self-Care**

Four participants (40%) identified salt/sodium as a CHF management, and the cover term was mentioned 22 times.

### ***Salt/Sodium Strategies***

Patient six identified salt/sodium strategies as “[Not having] it [salt] has become part of how I am,” and “I’ve just kinda [sic] replaced my salt for pepper and cayenne pepper and stuff like that.” Patient ten named salt strategies as “Know[ing] the sodium is really bad,” “[Using]

Mrs. Dash...[because] after you do it three or four months, your body's accustomed to it, and I think you gotta [sic] change your brain into thinking [it tastes good]," and "You've got to keep a journal. I keep a journal on things I eat."

### ***Salt/Sodium Needs***

Patient ten identified a salt/sodium need as, "educat[ing] people about what salt can do later on in life."

### ***Salt/Sodium Problems***

Patient eight named salt/sodium problems as cooking for a spouse, "I don't salt stuff when I cook for him, but it's just what I'm cooking would probably [have] more of it [salt]," as well as eating out and lack of willpower."

### ***Salt/Sodium Hindrances***

Patient ten noted a hindrance as, "If I didn't have heart failure, yeah, I wouldn't watch it [salt] at all." Patient one identified a salt/sodium hindrance as, "If [only] I could not crave salt."

## **Diet Self-Care**

Seven patients (70%) named diet as a CHF management strategy, need, problem and hindrance, and the cover term was elicited 85 times.

### ***Diet Strategies***

Diet strategies most mentioned included watching labels (patients four, six and eight) and eating at home/not eating out (patients two, six, seven, eight and ten). Patient six named a diet strategy as, "I try to stay away from sugars. I don't do no [sic] processed food." Patient ten identified diet strategies as, "I use grass-fed, no antibiotic-type chicken;" "I really try to look for the organic stuff now;" "I've ate [sic] a lot of fish, lot of greens, chia seeds, flax seeds. Yogurts;" and "I've been known to make my own salads, take my own cooler and put them in when I go to

Florida and see my daughter. I just refuse to do it [eat fast food].” Patient ten also identified overall motivation as a diet strategy: “Every day you got to get up and do it [eat heart-healthy diet] whether you want to or not;” “It’s just, I wanna [sic] be better;” “You don’t have to make the change all at once;” and “You have to get your mind and your brain on that [making positive changes], and constantly remind yourself.”

### ***Diet Needs***

Diet needs included having a cook (patients one, two and four), pre-planning (patient 6), limiting portions (patient 7), and the lack of knowledge about food additives (patient ten). Patient ten identified another diet need as “[having] a group thing where you can have a nutritionalist [sic] come once a month.”

### ***Diet Problems***

Diet problems included traveling, staying away from birthday parties and other special events (patients four, six and ten). Lack of willpower/temptation was named by patients one and six. Patient one said, “If it’s healthy, I don’t like it,” and “I just eat too much.” Patient six said, “Nothing’s easy,” and “It’s [lack of willpower] a lot [of not eating healthy]. That’s the temptation.” Finances were also named as a diet problem by patients one and six. Patient six said, “Towards the end of the month, it’s hard because you’re getting’ low on money and it’s usually the time I scrounge.”

### ***Diet Hindrances***

Diet hindrances were identified as having the wrong foods readily available (patient one), being too unmotivated to monitor food choices (patient six), and being at someone else’s home and not having the right foods to eat (patient ten).

## **Fluid Self-Care**

Only two patients (20%) identified fluid as a CHF management strategy, need, problem and hindrance, and the cover term was mentioned 15 times.

### ***Fluid Strategies***

Fluid strategies included keeping water readily available. Patient one said, “I carry it [water] with me a lot,” “I keep it [water] with me a lot,” “If we go out to eat, I drink water with my meal,” and “I try to keep a bottle of water in my car.” Patient two named a fluid strategy as knowing how much liquid was needed per day.

### ***Fluid Needs***

Fluid needs were identified as difficulty getting water while at work and having access to clean, pure water. Patient one said an ideal situation would be “if I had someone go get water for me while I was at work,” and “I’ve thought about asking the boss [to get water] a couple of times when it was really busy. And he would, but I’m like, ‘No, I can suffer.’ I’ve had him get me a bottle of water. But at work I keep a cup with ice in it.” Patient one also named a fluid need as not having “so much gunk [sic] in our faucet water.”

### ***Fluid Problems***

Fluid problems were named as being unable to “get up and get the water” at work, and not wanting to drink water unless it was at a certain temperature. Patient one said, “I like my water cold, so if it doesn’t have ice in it, then I don’t really want it.” Patient two stated just knowing “fluid intake is very important” was a problem, because patients have to be cognizant of the recommended daily amounts.

### ***Fluid Hindrances***

Patient two mentioned the only hindrance, which was drinking “city water. Oh, it’s

horrible, and I used to drink it and when I started putting it in a cup and I'd open the cup, oh my God, it smelled like bleach, then I couldn't drink it anymore."

### **Stress Self-Care**

Stress strategies, needs, problems and hindrances associated with CHF management were identified by three patients, or 30% of the participants. Stress was mentioned 19 times.

#### ***Stress Strategies***

Patient one named stress strategies as, "sometimes I just have to take a couple of deep breaths and just walk away from stuff;" patient six identified stress strategies as when she can, "Walk, talk, listen to music," and "make [her]self chill;" and patient ten said, "You need to take time for yourself. I don't care if it's two hours in the evening, figure it out."

#### ***Stress Needs***

Stress needs were identified as "more money," "less work," and "hav[ing] my housekeeper come more often," by patient one. Patient six named a stress need as "staying away from certain people."

#### ***Stress Problems***

Stress problems included, "[while at work] you can't just walk off," and finances (patient one), as well as "continued drama." Patient six said, "A continuance of a situation that I want to control, but I can't."

#### ***Stress Hindrances***

Stress hindrances for patient one were "medical bills," and for patient six, a stressful friendship.

### **Support Self-Care**

Three participants (30%) named support as a cover term for CHF management strategies,



needs, problems and hindrances, and support was mentioned a total of six times.

### ***Support Strategies***

Patient one named a stress strategy as her spouse. She said, “He’s very supportive. He’s not pushy. [He’s] just perfect,” and patient five identified a lack of support strategy as, “If I don’t take care of myself, then no one else is gonna [sic] take care of me.”

### ***Support Problems***

Patient one named support problems as “I don’t have any problems with support,” and “my past. It takes me a long time to realize...there’s my talking. It takes me a long time sometimes. I have to remind myself, because I’ve been in a lot of, what I would classify as abusive relationships, mentally abusive.”

### ***Support Hindrances***

Patient two named a support hindrance as not being able to be left alone “very long at a time.”

## **Medication Self-Care**

Medication strategies, needs, problems and hindrances associated with CHF management were identified by three patients, or 30% of the participants. Medication was mentioned 11 times.

### ***Medication strategies***

Medication strategies were identified by patient nine as having “a sorted pillbox...so I don’t take too much of one pill;” “It’s just I know it’s [medication] there and I gotta [sic] take it;” and “routine.” Patient ten identified strategies as, “taking my vitamins, [because] I think my medication works better;” and “I got [sic] pill boxes I set up weekly.”

### ***Medication needs***

Medication needs were named by patient two as having his “medicine delivered right here at the door, and patient nine as “when I’m having those dizzy spells, if somebody isn’t there to get my water [for me].”

### ***Medication Problems***

Patient ten named a medication problem as when “[I] run out [of medication] and [I do] not have the money to go get ‘em [sic].”

### ***Medication Hindrances***

Patient nine identified medication hindrances as, “[if I] wouldn’t have my medicine handy for me to get to...or not have my water to drink.” Patient ten said a hindrance was “being out with a friend and [forgetting] my medication at home.”

### **Blood Pressure Self-Care**

Only two patients (20%) identified blood pressure as a cover term for CHF management strategies, needs, problems and hindrances, and the cover term was mentioned a total of 15 times.

### ***Blood Pressure Strategies***

Patient three named blood pressure strategies as “the only reason I have to take my blood every day is Boston Scientific. I’m in a kind of clinical research study there. And that’s the only reason I have to do that every day;” “They [Boston Scientific] provide the blood pressure machine;” and “That’s [blood pressure machine] provided, and it’s electronic, and so it’s easy to do.” Patient ten identified blood pressure strategies as, “I write everything down, ‘cause [sic] something I eat that day, that next morning when my blood pressure’s up that much, it’s because of what I’ve done [sic] the day before;” “I never wanna [sic] face a heart attack;” “So, I think

every day, ‘Okay, if I get up and do this [take blood pressure], this keeps me from having one [heart attack].’ I don’t wanna [sic] be in pain;” “I got in the habit of writing down everything I ate, because it does factor into your blood pressure, your pulse;” and “Boston Scientific sent me the blood pressure cuff.”

### ***Blood Pressure Needs***

Patient three identified a blood pressure need as “if the configuration of our bedroom were a little different.”

### ***Blood Pressure Problems***

Patient ten named “being gone” as a blood pressure problem, while patient three identified problems as, “If my husband is still in bed;” “Our bedroom is not conducive to such a thing [taking blood pressure]. My husband usually is not up when I get up in the morning, and I don’t wanna [sic] disturb him because the blood pressure machine and the monitor, the telemetry device, is on his side of the bed;” and “If I’m on vacation or out of town for the weekend.” Patient ten also named “being gone” as a blood pressure problem.

### ***Blood Pressure Hindrances***

Patient ten identified a hindrance as “if I go without my CPAP machine, my blood pressure is horrible.”

## **Sleep/Rest Self-Care**

Sleep/rest strategies, needs, problems and hindrances associated with CHF management were identified by three patients, or 30% of the participants. The cover term sleep/rest was mentioned 20 times.

### ***Sleep/Rest Strategies***

Patient eight identified sleep/rest strategies as, “Whenever I need to, I’ll sleep in,” and “I

don't have any interruptions."

### ***Sleep/Rest Needs***

Patient seven identified a sleep/rest need as if "you [didn't] have anybody in your house but you," while patient eight said, "If I could stay home," and "be on my own schedule."

### ***Sleep/Rest Problems***

Patient six named sleep/rest problems as "the traffic [noise] out in the street," "neighbors," and "company." Patients seven and eight named sleep/rest problems, such as going somewhere [outside of the home], "[doing] something that breaks up the routine," "someone [who] comes to visit you," and "[doing] too much exercise, [and] then you have enough aggravation that you don't wanna [sic] sleep; you're not able to sleep as good."

### ***Sleep/Rest Hindrances***

Patient six named her kitten as a sleep/rest hindrance.

## **Weight Self-Care**

Three patients (30%) identified weight as a cover term for CHF management strategies, needs, problems and hindrances, and the term was mentioned a total of 18 times.

### ***Weight Strategies***

Weight strategies were identified as having an electronic scale provided by Boston Scientific (patients three and ten), and weighing "about the same time of day" (patient seven). Patient ten named weight strategies as, "It's [weighing] just out of habit now;" "It's [weight loss] the idea I wanna [sic] see what I've done. It's like an accomplishment;" "It's an accomplishment to say, 'Okay, I know I'm getting better...' Like my heart was 20% [functional] three years ago, today it's at 45, almost 50. So I think I contributed...It wasn't all drugs that did that; it was a lifestyle change that I had to make;" and "You're gonna [sic] have to get up and help yourself,

doctors can only help you so much.”

### ***Weight Needs***

Weight needs were identified as having a different bedroom configuration (patient three), and having a scale visible first thing in the morning as a reminder (patient ten). Patient ten said, “I look at it [scale] first thing in the morning, so yeah, I go ahead and do it [weigh].”

### ***Weight Problems***

Patient three named weight problems as, “I’m supposed to [weigh], but I don’t every day ‘cause [sic] I don’t like to;” not having willpower, “I watch the food go in my mouth;” and not being able to watch diet when out of town. Patient ten identified a weight problem as “being gone [out of town],” and a weight loss problem as “I’ve got big ‘ole [sic] wings now [extra skin due to considerable weight loss].”

### ***Weight Hindrances***

Patient three mentioned the only weight hindrance as, “If I were thin and svelte.”

## **Exercise Self-Care**

Four participants (40%) identified exercise as CHF management strategies, needs, problems and hindrances, and the cover term was mentioned 39 times.

### ***Exercise Strategies***

Exercise strategies included, “When I’m on my bike, he [spouse] encourages me to continue. Not stressful like, but, ‘You can make it one more minute,’ that kind of thing. He does real good [sic] with that,” and watching a program on TV while exercising (patient one); “I try to walk every day,” sometimes with her dogs (patient six); “I’ve been trying to use the treadmill a little bit,” “always [walking] to get the mail,” taking the trash out, “it’s a pretty little walk back and forth that way,” and having a garden (patient seven). Patient ten named exercise strategies as

keeping “a day-to-day routine;” “The idea I wanna [sic] live, and my heart needs to get better...So, I continue to exercise and figure out [my] own diet;” “you’ve just got to have the drive;” taking pain pills as needed [for osteoarthritis in joints]; “[walking] the dogs;” “Yoga’s helped me a lot...you kinda [sic] listen to what the body’s telling you;” “Yoga has taught me how to breathe as you exercise...Breathing exercises do help;” and “If I got any sicker, I’d probably try [to exercise] harder.”

### ***Exercise Needs***

Exercise needs were named as having a friend or someone to exercise with (patients one and six); owning own exercise equipment (patients six and ten); understanding exercise benefits not only weight but heart health (patient ten); “flexible scheduling” (patient one); and “if I felt better [exercise would be easier]” (patient seven).

### ***Exercise Problems***

Exercise problems included “the weather” (patients six and ten); lack of motivation, “I sit on the couch and then my butt just doesn’t want to get up,” (patient one); problems associated with living with a chronic condition, “When I am too short of breath, I just can’t...There’s a limit to what I can do,” and not feeling well, “Like today, [I had] a bad headache, and you’re halfway dizzy, so you just don’t get out there and do it [exercise] (patient seven).

### ***Exercise Hindrances***

Patient one identified an exercise hindrance as having distractions. She said, “If I didn’t have a TV, I probably wouldn’t sit in there, and I probably would wanna [sic] get on the bike.”

## **Overall Self-Care**

Seven participants (70%) identified overall CHF management strategies, needs, problems and hindrances, and the cover term was mentioned 52 times.

### ***Overall Strategies***

Overall strategies included making a lifestyle change. Patient two said, “It’s [living with CHF] just kind of a way of life,” and “You learn to adapt to it. You know that this is life and this is what you have to do. And you can’t run away from it.” Patient seven said, “I’ve got to do it [follow CHF recommendations].” Patient ten said, “It’s [making a lifestyle change] not something I wanted to do; it’s something I had to learn to do;” “When you have congestive heart failure, you’re gonna [sic] have to make a lifestyle change;” and “I’ve gotten better. And I’m gonna [sic] continue. Everybody says, ‘You can’t beat it [congestive heart failure].’ Yes, you can. You can beat it but you’ve got to have the drive to beat it.” Overall strategies for patient five included following a set schedule. He said, “Everything happens first thing in the morning;” “I just have a regular schedule;” “Having spent 20 years in the Army, there’s a regimen, and I follow the regimen;” “You just get up and do whatever you need to do;” and “So there’s a way I do things, and as long as you don’t skip a step, I’m alright.”

Patient ten also commented that living on the West Coast prior to moving to the Midwest was a strategy. She said, “Being on the West Coast, we don’t have all these fast foods. McDonald’s are hard to find; Carl Jr.s are hard to find. I think if you would go to Arizona or California, and just sit at a Wal-Mart and look at the people that walk in there, and then come back here [to the Midwest]...and look at the people that walk into Wal-Mart here, you would understand.” She also identified keeping a journal as a strategy. She said, “I think it’s important for anybody that has congestive heart failure, diabetes, emphysema, COPD, [etc.], it’s important to keep a journal of what you eat, what you did that day, how far you’ve walked, if you went to the gym or not, what times you spent there. Make you [sic] a log, make you [sic] an agenda every day.” Finally, she listed an overall strategy as motivation, because “now that you’re on the

right track and doing downhill with the weight, it makes your heart stronger.”

### ***Overall Needs***

The participants identified overall CHF needs as having doctors make house-calls, having better parking options at the medical clinic and having transportation to doctor’s appointments (patient two); knowing “There’s nothing that makes it easier, because you can’t alter anything. You just have to let what’s wrong with you...If it’s gonna [sic] change, that’s the only thing you can do, is wait for it to change, ‘cause [sic] you can’t alter it,” and having the time to do it (patient five), and having “unlimited money” (patient six).

Patient ten identified overall CHF needs as largely based on educational needs, which included cultural awareness, education about chronic disease earlier in life, and providing support for people who are experiencing chronic conditions. She said, “I never noticed it so much whenever I was so overweight ‘cause [sic] there was [sic] so many people like me, but then after I lost a lot of weight and I got to looking at ‘em [sic], and they’re walking in from just the parking lot, it’s like they can’t even breathe. You see that, and they grab those electric wheelchairs, and I’m going, ‘Wow!’ And, the stuff you see in their carts, and I’m going, ‘I used to buy that. Don’t they realize what they’re eating?’ And, I wanna [sic] go up to them, and going [sic], ‘Hey, you shouldn’t really eat this.’ But, you can’t do that in society today. Out West, yeah, you could ‘cause [sic] everybody discusses and you don’t see a lot of that. And, being out there 15 years and then moving back here, I was going, ‘Does everybody in this town weigh over 300 [pounds]?’” She also said, “People out there [out West] is more [sic] geared to taking care of theirself [sic]. You don’t see a lot of congestive heart failure; you don’t see a lot of the COPD. People are more exercised [sic], and I think that’s where I got into it more, is [sic] to be out there. I think a lot of it’s the culture, whichever area you’re in;” and “The best thing that ever



happened was me moving out West, staying out there so long, and learning from those people of what to do.”

Other overall CHF needs patient ten identified were, “I wanna [sic] see what I can accomplish now... Basically, I call it a road to recovery... It’s a therapeutic thing, and I think you gotta [sic] change your mind.” She also mentioned educational and support opportunities as needs. She said, “I think it [information on diet and exercise] should be in stowed in high schools... in the Midwest especially;” “If people would talk to each other more, like if we had a group, to get a group together, that could talk every [sic] once a week about what they do;” “I think a support group, I think they should try to have, for people with CHF. I know they have one for diabetics, but I also think that congestive heart failure, diabetics [sic] and emphysema and COPD, it all goes together in one. “Cause [sic] usually, if you get one, you’re going to get the other;” and “Every individual needs to put education together with it, and I think that [there] needs to [be] a group thing to where you can have a nutritionist [sic] come once a month, [or] every once a week.”

### ***Overall Problems***

Overall CHF problems included the following: just not feeling well and CHF mimicking COPD symptoms (patient two); not doing anything, “I don’t have to do anything, as far as I know,” (patient three); “If I’m sick, something like that, then I probably [would] omit doing this [following CHF best practices], because I just don’t have the strength... to do it,” and “Just not having the desire. And therein lies part of the situation with this [having CHF], because if you lose your desire, it’s not gonna [sic] do you any good. It’s gonna [sic] hurt you worse than it’s gonna [sic] help you,” (patient five); and “It’s a culture shock. It is a culture shock from the West Coast to the Midwest; it really is. I was amazed,” and “It’s just hard; it’s nerve-wracking, and

I'm, 'Oh, I've gotta [sic] do this today. Why do I have to do this every day?' And, then I go, 'Well, if I'd taken good care of myself back when I was younger, I wouldn't be in this position today,'" (patient ten).

### ***Overall Hindrances***

Many participants (40%) named an overall CHF hindrance as not having the disease. Their comments were as follows: "If [I] didn't have it at all. That would be the perfect thing, if [I] didn't have this at all;" "I think just being healthy would be ideal," (patient two); "The situation would not be here," (patient three); "If I didn't have the disease," (patient four); and "[I wouldn't have] a bad heart," and "If I didn't have a bad heart, I'd probably do a lot of things differently," (patient seven).

Other overall CHF hindrances included, "If I felt unsafe. If I had fallen, or an accident had happened around the house," and "[If] family would come over, and that would alter my schedule," (patient five); and when diagnosed, "now all of a sudden, they're throwing all this stuff at you that you've gotta [sic] do, and it's overwhelming, and not to say the least, it's very, very overwhelming," (patient ten).

### **Summary**

This chapter presented the findings of the perceived motivators and inhibitors of performing self-care by rural patients living with congestive heart failure (CHF). Best practices for self-managing CHF include taking medications daily; weighing daily; checking blood pressure daily; watching daily fluid intake; limiting alcohol and caffeine; losing weight (if needed); following a heart-healthy diet that is low in sodium; eating fewer salty or sodium-filled foods; exercising and getting plenty of rest (American Heart Association, 2015).

Using the HEM elicitation (domain) analysis, participants identified the following cover

terms and included terms: congestive heart failure (CHF) management activity, lack of CHF management activity, medication, sleep/rest, diet, exercise, fluid, salt/sodium, stress, support, CHF overall management activity, blood pressure, weight, and the outliers of staying indoors, staying out of the cold, moving from different state, knowing limitations and reading pacemaker.

As part of qualitative research, quotations from the participant interviews were included in this chapter. Preserving the participants' language contributes to the overall validity of the study and accurately describes the perceptions of a culture-sharing group (Nardi & Harding, 1978; Harding & Livesay, 1984).

## **Chapter 5**

### **Conclusions and Recommendations**

#### **Overview**

The purpose of this ethnographic study was to identify contributing factors, situations or conditions that facilitate or impede rural residents who are living with a chronic disease in performing and/or completing self-care practices at home. The conclusions from this study are based on the research question and findings. The following conclusions are derived from the participants' responses during the one-on-one interviews and the researcher's assumptions of the study, which include (1) participants' understanding of CHF, (2) participants' ability or desire to make lifestyle changes, and (3) the role of a support system in participants' CHF self-care.

#### **Research Question**

The present study sought to address the following research question:

1. How do congestive heart failure patients living in a rural area perceive their ability to perform self-care measures at home?

#### **Participant Understanding of CHF**

The researcher's first assumption was rural patients do not have a thorough understanding of their chronic disease or what steps they need to take to self-manage their CHF at home. The researcher suspected limited understanding of chronic conditions might be due to the following factors identified in the literature as prevalent in rural communities: lower education levels, lower median income, and chronic conditions affecting an older population (Missouri Hospital Association, 2011). The researcher found all three factors present in the current research study. The study's participants were predominately high school graduates or had earned a high school

equivalency diploma (62.5%); were 65 years or older (62.5%); and reported an annual income of \$34,999 or less per year (62.5%).

The cover terms most mentioned by the participants through the HEM elicitation phase (domain analysis), included the following: CHF management activity; lack of CHF management activity; medication; sleep/rest; diet; exercise; fluid; salt/sodium; stress; support; CHF overall management activity; blood pressure; and weight. However, none of the participants listed all of the cover terms as activities for their own self-management at home. Limiting alcohol and caffeine were not mentioned by any of the participants as a best practice, although it is recommended as a CHF self-management strategy by the American Heart Association. Similarly, 30% of participants identified having support and limiting stress as a CHF management activity, although these strategies are not identified by the American Heart Association as CHF best practices.

Hence, within this study, participants did not know, or neglected to mention all of the daily best practices recommended for CHF patients. Only 30% of participants identified taking medications daily; 30% identified weighing daily; 20% identified checking fluid levels daily; and 20% identified taking blood pressure daily. Frequent reasons for weighing daily or taking blood pressure daily were due to the participants being provided an electronic scale or blood pressure cuff and not because these daily activities were effective self-management practices.

Although participants identified cover terms for CHF self-management, the included terms and responses were often vague. For instance, 70% of the respondents named diet as necessary for managing CHF, but how they did not elaborate on how they managed their diet. Verbatim responses included, “The only difference [CHF lifestyle change] is my diet,” “[I] eat proper;” “[I] really have to watch [my] diet;” “I try to eat better;” “I eat at home and watch

labels;” “eating good;” “being at home and cooking well;” “I try to watch my diet with the low salt;” and “I do follow a good diet.” Specific examples, such as salt intake per day, the types of foods considered heart healthy, particular diets, and what types of foods are/are not recommended were rarely mentioned.

Participants also frequently identified CHF simply as, “A way of life;” “It’s just kind of a way of life;” “It has become part of how I am;” but specific examples of how CHF had necessitated lifestyle changes, or became a “way of life,” were rarely mentioned. One participant answered the initial interview question on the different kinds of things performed at home for CHF self-care by saying, “I don’t do [sic] anything...I don’t do [sic] anything, particularly.” The same patient later stated, “I don’t have to do anything, as far as I know.”

Based on the responses, one might infer within the present study, socioeconomic factors such as, finances, age and education did play a role in how rural residents living with a chronic condition perceive/understand their conditions and influence the outcomes of how they perform self-care measures at home.

### **Ability or Desire to Make Lifestyle Changes**

The researcher’s second assumption that guided the present study was that although patients may have the desire to change, they may not know what steps to take to initiate change. In addition, within the present ethnographic study, the researcher found that managing a chronic condition may be influenced by certain values, behaviors and beliefs held by a rural demographic. For instance, healthcare avoidance, limited resources, limited education, financial concerns, not having an established primary care provider, fear of the unknown, low priority and lack of support have all been cited as barriers to adhering to healthy lifestyle changes in a rural population (Campbell et al., 2014; Logan et al., 2013; Spleen et al., 2013; Murimi & Harpel,

2010). A chronic condition can be overwhelming, and patients may not know where, or how, to start making positive changes towards a healthier lifestyle (Mead, Andres, Ramos, Siegel, & Regenstein, 2010). Only one participant identified feeling overwhelmed when diagnosed. She said, “Now all of a sudden, they’re [doctors] throwing all this stuff at you that you’ve gotta [sic] do, and it’s overwhelming, and not to say the least, it’s very, very overwhelming.”

Following the 10 participant interviews, the researcher viewed two (20%) participants as taking a more engaged approach to self-managing their CHF, while the majority of the participants took a less-engaged approach to their conditions. The two engaged patients were more likely to elicit responses indicating personal responsibility and empowerment over their disease. One of the patients was retired military, which influenced his values and beliefs on how to self-manage his CHF for 35 years. For him, the motivating factor was “all in the schedule.” He repeated throughout the interview that he followed his routine without fail, in order to ensure he was doing everything he needed to do to manage his CHF on a daily basis. He said, “I always wake up at just about the same time, and I just have a schedule, and it’s just, my day is planned.” He also lived alone and acknowledged he was the only one responsible for his health. He said, “If I don’t take care of myself, then no one else is gonna [sic] take care of me.”

The second patient had only been diagnosed with CHF for three years, and she also had specific values and beliefs which guided her motivation to self-manage her CHF. One of these beliefs was maintaining a schedule and journal to help track her success with daily management. She said, “It’s just a day-to-day routine,” and “Everyday you’ve got to get up and do it, whether you want to or not.” She advocated keeping a journal to keep track of exercise and daily food intake, and attributed living in a different geographical area of the United States as a factor in helping her learn how to eat more healthfully. She also believed education about chronic disease

should be promoted at an earlier age, and she acknowledged the need for a local support group for CHF patients. She admitted a healthier lifestyle was “not something I wanted to do; it’s something I had to learn to do,” and she took responsibility for not living a healthier lifestyle earlier in her life. She said, “If I’d took [sic] care of myself back when I was younger, I wouldn’t be in this position today.”

In concordance with the literature on rural populations, many of the participants acknowledged their chronic condition with “stoicism” and “fatalism” (Gessert et al., 2015). Four of the participants with a less-engaged approach identified an ideal situation for self-managing their CHF as never being diagnosed. Their comments included, “If [I] didn’t have it at all. That would be the perfect thing, if [I] didn’t have this at all;” “I think just being healthy would be ideal;” “If I felt better;” “The situation would not be here;” “If I didn’t have the disease;” “[I wouldn’t have] a bad heart;” and “If I didn’t have a bad heart, I’d probably do a lot of things differently.” These comments were surprising, because while not having CHF is an ideal situation, it is not realistic, as CHF is treatable, but not curable. Instead of identifying certain factors, tools or resources that might help ease or facilitate home self-management, patients wished for an impossible outcome. The unattainable ideal situation may have been acknowledged because these patients may have had a limited knowledge of CHF overall, and thus not have known what they would need to help self-manage their disease or make healthier lifestyle choices.

In the present study, having CHF was largely deflected as beyond their control, to chance, or “just the way life goes” instead of a result of prior lifestyle choices and/or other contributing factors. Many of the participants did not seem to make a connection between making poor choices earlier in life and the onset of heart failure later in life. Only one participant



acknowledged not making good lifestyle choices was directly responsible for her diagnosis of CHF as an older adult.

### **Role of a Support System in CHF Self-Care**

The researcher's third assumption was patients with chronic conditions might not be able to make, or sustain, healthy lifestyle changes if they do not have an established support system. The literature pointed to family, friends, or a trusted healthcare provider as examples of the types of support needed in chronic disease self-management (Lofvenmark, Karlsson, Edner, Billing, & Mattiasson, 2011; National Prevention Strategy, 2011; Mead et al., 2010; Clark et al., 2009). However, within the present study, the researcher found no strong link between support and self-management compliance, or the extent to which a patient follows medical advice.

The two participants identified by the researcher as being the most proactive with their CHF were not married. One was widowed and the other was divorced. While both mentioned having family in the interviews, there was not a specific person, or group of people, who they attributed with helping them in daily CHF self-management. For them, keeping a schedule was a necessary factor to completing self-care activities at home. One of these two patients acknowledged a positive relationship with her cardiologist. She said her cardiologist told her, “‘You’re gonna [sic] have to get serious about how long you want to live, ‘cause [sic] there is only so much I can do. You’ve got to help yourself with this,’” and, “‘you’ve got to help us help you. It’s a circle of life. It goes around in circles. If you don’t wanna [sic] be part of the circle, then get off the merry-go-round.’” She said his honesty “was kind of an eye-opener.”

In the present study, a spouse, or more specifically, a husband did not seem to help facilitate effective CHF self-management practices. Many of the female participants who were married altered their needs and/or the recommended CHF best practices to accommodate their

husbands' lifestyles. The literature suggested "the ability to work and to fulfill (traditional) social roles" is important to rural individuals (Gessert et al., 2015), which may account for the values of several of the female participants. Responses included the following: "I have to consciously do things, because if I cook, I cook mostly for him. That's not the things I should be eating;" "We have a tendency to sit in the living room and watch TV, which is the worst thing you can do;" "He's [spouse] is gone during the week, so I can do better, but when he's home, it's hard to, you know...He wants good food;" "I don't salt stuff when I cook for him, but it's just what I'm cooking would probably [have] more of it [salt];" and, "My husband usually is not up when I get up in the morning, and I don't wanna [sic] disturb him, because the blood pressure machine and the monitor, the telemetry device, is on his side of the bed."

"Religious or spiritual health" also often shapes values and beliefs in a rural area (Gessert et al., 2015). Although all the respondents who participated in the demographic survey affiliated with a religious practice, none of the participants mentioned religion as influencing their health choices. However, following the interviews, two individuals did acknowledge their spiritual beliefs helped them manage their chronic conditions.

The findings in the present study indicated the implementation of a schedule and self-motivation as definitive factors for effectively self-managing CHF at home. As one participant noted, "If anyone has this [CHF], if they don't do [sic] a lifestyle change, yes, it's gonna [sic] put [them] sitting in front of the TV all [of] the time. But, you're gonna [sic] have to get up and help yourself; doctors can only help you so much. If you wanna [sic] live a long longevity..." "You've got to have the drive."

Also, the findings suggested traditional family roles and religion may also contribute to the beliefs and attitudes about health and chronic disease self-management in a rural population.

## **Recommendations**

The researcher presents the following recommendations based on the participant one-on-one interviews, data analysis and conclusions of this study. The recommendations are for current healthcare administrators, physicians and educators, and future research.

### **Healthcare Administrators, Physicians and Educators**

Healthcare administrators, physicians and educators could consider the following:

1. Examine the role and effectiveness of the Chronic Disease Self Management Education (CDSME). Patients with CHF should be highly encouraged to attend a CDSME program, along with their support systems, upon diagnosis of the disease. The healthcare facility in Rolla, Missouri, where participants were recruited for the study, offers a 12-week CDSME program several times per year. Participants can take the class at no cost to them. Information about the CDSME program could be given to patients upon diagnosis.
2. Following completion of the CDSME program, there could be a follow-up system established, where healthcare professionals or trained lay people check-in with the patient at regular, designated intervals in order to help answer questions and concerns, as well as promote self-care compliance, or the extent to which a patient follows medical advice in order to care for him/herself. The literature suggests patients have a better chance of self-managing their chronic conditions if they have on-going support from family, friends, healthcare providers or lay professionals (Cene et al., 2015; Khare et al., 2014; Peek et al., 2014; Rosland et al., 2013; Sayers et al., 2008).
3. CDSME programs must not be “one size fits all.” The chronic disease self-management program could include a number of classes, according to the stage of the

chronic disease. The patients' education must evolve as their diseases progress, because chronic conditions change over time; hence, patients' requirements and the amount of support needed may change over time (van Houtum et al., 2013; Auduly et al., 2010).

4. Community education about chronic disease could be ongoing and not only available to patients at the time of diagnosis. Preventive community education programs could address the importance of establishing primary care and preventive exams; strategies for living a healthy lifestyle, to include applicable examples and/or plans; recognizing symptoms and identifying risk factors; and knowing the importance of not waiting to access medical care at the onset of symptoms. The literature suggested engaging in preventive care services, which are tests, screenings, vaccinations, patient counseling and regular visits to a primary care provider, are used to "prevent illnesses, disease, and other health problems, or to detect illnesses at an early stage when treatment is likely to work best" (Centers for Disease Control and Prevention, 2015, p. 1).
5. Promote patient empowerment. Patients could be told and consistently reminded they are a vital part of their healthcare team. Their compliance (the extent to which they follow medical advice) is critical to optimal health outcomes, and they need to be told they are their own best advocates. For example, "You have 'x' disease. You are not 'x' disease." They need to understand there is life outside of diagnosis, and healthcare compliance is an evidenced-based way to improve quality of life. The National Prevention Strategy (2011) suggested when patients feel empowered, they are more likely to take an active role in making healthy choices and initiating lifestyle changes.

6. Use simple, everyday language when discussing diagnosis, treatment, best practices, compliance goals, etc. Incorporating visuals, along with the use of simple language, may further increase or help patient understanding. Based on the present study, language used above a high school diploma or high school equivalency would not be ideal.
7. Recognize cultural and/or gender factors may be indicative of patient compliance (the ability to follow medical advice). For example, based in the present study, people who lived in a different area and moved to a rural area may be more receptive to initiating healthy lifestyle changes. Also, based on the present study and existing literature (Gessert et al., 2015; Salyer, Schubert, & Chiaranai, 2012; Riegel, Lee & Dickson, 2011; Kristofferzon, Lofmark, R., & Carlsson, 2003), women living in a rural area may be more prone to putting their health needs second to their spouse or how they view their social roles.
8. Provide patients upon diagnosis with the equipment needed for daily self-management, such as an electronic scale and blood pressure machine. The present study showed some patients were more likely to comply with weighing or taking blood pressure daily, simply because the machines were readily available.

### **Future Research**

Further research opportunities are as follows:

1. Identify whether rural patients who completed a CDSME program upon diagnosis of their disease experienced better overall healthcare compliance, or the ability for patients to follow medical advice, and chronic disease symptom management. The literature suggested CDSME may contribute to better overall healthcare outcomes

(Cene et al., 2015; Khare et al., 2014; Peek et al., 2014; Rosland et al., 2013; Sayers et al., 2008).

2. Explore what factors motivate or inhibit patients from following medical advice and/or recommendations, as well as achieving and sustaining change in general. Compare and contrast proactive patients with less-engaged patients to discover similarities, differences, behaviors or patterns. The findings could indicate factors that motivate and inhibit patients from following medical advice and healthy lifestyle recommendations; hence, the findings could benefit policy for healthcare organizations and community health education.
3. While the role of marital influence is cited as a contributing factor in the compliance of women with chronic disease (Salyer, Schubert, & Chiaranai, 2012; Riegel, Lee & Dickson, 2011; Kristofferzon, Lofmark, R., & Carlsson, 2003), further research could be conducted to address the role and influence of marital status in women living in rural areas. Further study may indicate why women in rural areas mesh their personal identity within a specific, traditional social role.
4. A study could be undertaken to examine the impact of influence of geographic culture, identity and sense of place in patients living with chronic disease. This research could help identify similarities or differences in the perceptions of chronic disease in patients living in different regions of the United States. The findings could inform potential strategies for healthcare professionals to engage patients living in rural areas to follow healthcare recommendations or initiate lifestyle changes.

## **Lessons Learned**

The researcher recommends the following changes to the present study:

1. Phrase the interview questions differently. The researcher would take into consideration the demographics of a rural participant population and make sure the interview questions were created on an eighth grade level. In addition, instead of asking the participants questions about multiple environmental influences (e.g. conditions, factors, tools or situations, in the present study), the researcher would choose only one. For example, (a). What situations make it easier to do “x”? [answers = y] Probe: What else makes it easier to do “x” other than “y”?
2. Have other questions planned to get the participants talking in case the interviews do not go according to plan. For instance, if they do not understand the question, have another question ready to ask and keep the question consistent. For instance, if a participant answers, “I don’t do anything,” then the researcher could say, “Tell me more about how you do not do anything to do “x.” Then, the participants are still answering the question. Even if they specify how they do not perform “x,” they are still informing the study.
3. Recognize even if the interviews and the participants’ answers are vague and/or they do not answer much or elaborate, their answers are still informing the study. The interviews may not go according to plan, but any answer they give provides information and offers potential areas for further research.
4. Consider traditional social roles and/or marital situations. Based on the present study, participants may change their answers to accommodate their spouse, family member or friend. Participants may not be entirely truthful if their spouse (or another individual with whom they have a close relationship) is seated next to them. For

future studies, the researcher recommends requesting only the participant is present during the interviews.

## **Summary**

The results of this ethnographic study provided some insights into the perceptions of rural patients living with congestive heart failure about their abilities to self-manage their conditions at home. While socioeconomic factors, such as education level, income and age contributed to overall healthcare compliance, other factors not considered by the researcher, such as gender roles, total non-compliance of medical advice, and lack of understanding of the interview questions also influenced the present study. However, the study did offer areas for future research, such as implementing/modifying chronic disease education programs, examining the influence of geographic culture, examining traditional social roles in rural areas, and identifying ways to help motivate less-engaged patients in their healthcare.



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## Appendix A

### Interview Worksheet

Date:

Name:

Q1: What are the different kinds of things that you do, or try to do, to take care of your congestive heart failure at home?

[Answers = X]

1.

2.

3.

4.

5.

6.

7.

8.

Q2: For/When X [plug in Q1 individual tasks], what conditions, factors, tools or situations make it easier to conduct X?

[Answers = Y]

1a.

2a.

3a.

4a.

5a.

6a.

7a.

8a.

Q2 Probe: What else makes it easier to conduct X [plug in Q1 individual tasks] other than Y? [plug in Q2 answers]

1aa.

2aa.

3aa.

4aa.

5aa.

6aa.

7aa.

8aa.

Q3: For/When X [plug in Q1 individual tasks], what conditions, factors, tools or situations make it difficult to conduct X?

[Answers = Y]

1a.

2a.

3a.

4a.

5a.

6a.

7a.

8a.

Q3 Probe: What else makes it difficult to conduct X [plug in Q1 individual tasks], other than Y? [plug in Q3 answers]

1aa.

2aa.

3aa.

4aa.

5aa.

6aa.

7aa.

8aa.

Q4: What conditions, factors, tools or situations have not allowed you to do X ? [plug in Q1 individual tasks] [Answers = Y]

1a.

2a.

3a.

4a.

5a.

6a.

7a.

8a.

Q4 Probe: What else has not allowed you to do X [plug in Q1 individual tasks], other than Y?

1aa.

2aa.

3aa.

4aa.

5aa.

6aa.

7aa.

8aa.

Q5: What conditions, factors, tools or situations would make the ideal situation to conduct X ? [plug in Q1 individual tasks] [Answers = Y]

1a.

2a.

3a.

4a.

5a.

6a.

7a.

8a.

Q5 Probe: What other conditions, factors, tools or situations would make the ideal situation for you to do X [plug in Q1 individual tasks], other than Y?

1aa.

2aa.

3aa.

4aa.

5aa.

6aa.

7aa.

8aa.

Q6: What conditions, factors, tools or situations would the ideal situation not have, or avoid, in order for you to conduct X ? [plug in Q1 individual tasks] [Answers = Y]

1a.

2a.

3a.

4a.

5a.

6a.

7a.

8a.

Q6 Probe: What other conditions, factors, tools or situations would the ideal situation not have, or avoid, for you to do X [plug in Q1 individual tasks], other than Y?

1aa.

2aa.

3aa.

4aa.

5aa.

6aa.

7aa.

8aa.

## Appendix B

### Domain Definition

Included Term	Semantic Relationship	Cover Term
Mostly nothing	is a kind of/is a type of	lack of CHF management activity
I don't do anything		lack of CHF management activity
Take my medication		CHF management activity
Rest a lot		CHF management activity
Plenty of rest		CHF management activity
Try to get rest		CHF management activity
Get sleep		CHF management activity
Watch my diet with low salt		diet CHF management activity
Eat proper		diet CHF management activity
My diet		diet CHF management activity
Follow a good diet		diet CHF management activity
Try to eat better		diet CHF management activity
Watch what you eat		diet CHF management activity
Eat healthy		diet CHF management activity
Stay away from red meats		diet CHF management activity
Stay away from GMO products		diet CHF management activity
No salt		CHF management activity
No salt		CHF management activity
Watch my salt intake		CHF management activity
Watch the sodium		CHF management activity
Keep my weight stable		CHF management activity

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
Watch my weight	is a kind of	CHF management activity
Weigh myself every morning		CHF management activity
Weigh myself		CHF management activity
Exercise if I can		CHF management activity
Make sure I walk		CHF management activity
Try to exercise		CHF management activity
Started an exercise program		CHF management activity
Walk		CHF management activity
Ride my bike		CHF management activity
Go to the fitness centers/gym		CHF management activity
Exercise at home		CHF management activity
Try not to stress		CHF management activity
Try not to let things stress me out so much		CHF management activity
Have blood pressure taken		CHF management activity
Take my blood pressure every day		CHF management activity
watch blood pressure		CHF management activity
Take my blood pressure every day		CHF management activity
Fluid intake		CHF management activity
Drink lots of water		CHF management activity
Gave up soda (except for one drink a day)		CHF management activity
Watch the vitamin K		CHF management activity
Take quite a few vitamins		CHF management activity
Take a B12		CHF management activity
Can't go outside in the cold very much		CHF management activity
Stay inside basically		CHF management activity

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
Support	is a kind of	CHF management activity
Moved back to Missouri (from Arizona)		CHF management activity
Know my limitations		CHF management activity
Reads pacemaker		CHF management activity



<b>Included Term</b>	<b>Domain Analysis Semantic Relationship</b>	<b>Cover Term</b>
If I go without my CPAP, my blood pressure is horrible	is a kind of/is a type of	blood pressure hindrance
if the configuration of our bedroom were a little bit different		blood pressure need
our bedroom is not conducive		blood pressure problem
I don't want to disturb him because the blood pressure machine and monitor, the telemetry device, is on his side of the bed my husband's still in bed		blood pressure problem blood pressure problem
if I'm on vacation or out of town for the weekend		blood pressure problem
being gone		blood pressure problem
the only reason I have to take my blood pressure every day is Boston Scientific. I'm in kind of clinical research study there.		blood pressure strategy
they provide the blood pressure machine		blood pressure strategy
it's provided, it's electronic, and it's so easy to do		blood pressure strategy
I write everything down		blood pressure strategy
the idea that I never wanna face a heart attack		blood pressure strategy
I don't wanna be in pain.		blood pressure strategy
that's where I got in the habit of writing down everything I ate, because it does factor into your blood pressure, your pulse.		blood pressure strategy
Boston Scientific sent me the blood pressure cuff		blood pressure strategy
Not have candy and stuff, bad things laying around		diet hindrance
I'm just too lazy to do it		diet hindrance
if I was at someone else's house and they didn't have the right stuff that I can eat		diet hindrance

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
If I had a cook	is a kind of	diet need
Unlimited budget, meal budget		diet need
Lots of time to cook		diet need
it'd be perfect if somebody would cook it and bring it here and say "X, here is your breakfast. I'll be back later with lunch," and is off, that would be wonderful		diet need
They have to be all frozen, not canned		diet need
If I had a cook in the house. Somebody else doing it for me.		diet need
pre-planning		diet need
you just limit yourself to what, in other words, your amounts, the portions you have		diet need
just being at home and cooking well		diet need
we really don't know what's in that [food], we really don't		diet need
you could get it from just food, if it was plentiful here		diet need
needs to have a group thing to where you can have a nutritionalist [sic] come once a month		diet need
I can't think of any		diet problem
We're picky eaters		diet problem
If it's healthy, I don't like it		diet problem
I just eat too much		diet problem
I don't like any of the good food		diet problem
Budget		diet problem
that it's hard to do [diet]		diet problem
I have to watch what I eat		diet problem
when we go out and eat		diet problem
sometimes you just get hungry for a sweet treat		diet problem
cause most of the food has hidden salt in it		diet problem
when we're traveling		diet problem
money		diet problem
if I happen to go out to eat		diet problem
holidays, birthday parties		diet problem

Included Term	Semantic Relationship	Cover Term
towards the end of the month, it's hard because you're getting' low on money and it's usually the time I scrounge	is a kind of	diet problem
because you got to eat lean, but you can't. you can eat fruits and such as that, but not much. And if there's anything...dark vegetable, you can't have at all		diet problem
nothing's easy		diet problem
eating out, that's a big factor		diet problem
watch and eat prepared food		diet problem
eating out		diet problem
he's gone during the week, so I can do better, but when he's home, it hard to, you know		diet problem
Being out and about		diet problem
me and potatoes have a royal fight each week		diet problem
it was normal for me, but it wasn't normal for my body		diet problem
church dinners, holidays, birthdays		diet problem
I have to consciously do things		diet strategy
There are a few things I've learned to like, or learned to tolerate		diet strategy
You really have to watch his diet		diet strategy
don't add any extra salt		diet strategy
watch the labels		diet strategy
go out and have something to eat		diet strategy
I cook at home		diet strategy
try to stay away from sugars		diet strategy
I don't do no processed food		diet strategy
very seldom drink soda		diet strategy
I watch sodium labels		diet strategy
every now and then I want cheese. I don't do it very often		diet strategy
eating good		diet strategy
it's just part of the way of life		diet strategy
u don't go someplace else and eat a lot of stuff that you shouldn't eat		diet strategy

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
I'm in the habit of doing it	is a kind of	diet strategy
it's a way of life		diet strategy
just trying to eat at home more		diet strategy
just the eating at home, not salting		diet strategy
you can do your own seasonings		diet strategy
I watch labels		diet strategy
I eat at home and watch labels		diet strategy
I use grass-fed, no antibiotic-type chicken		diet strategy
I really try to look for the organic stuff now		diet strategy
I've ate a lot of fish, lot of greens, chia seeds, flax seeds. Yogurts.		diet strategy
it's because I know what this disease done to my generation		diet strategy
doctors tell me "You got to lose weight, you've got to do it.		diet strategy
I've been known to make my own salads, take my own cooler and put them in when I go to Florida and see my daughter. I just refuse to do it [eat fast food].		diet strategy
I think taking the vitamins also helps with me not over eating the food		diet strategy
I go every two, three days still [to Aldi's], but I wanna get the freshest		diet strategy
I think lemon-water has a lot to do with it		diet strategy
you have to stay on that all the time		diet strategy
every day you got to get up and do it whether you want to or not		diet strategy
it's just, I wanna be better		diet strategy
I was glad to be part of that culture because I brought it back here		diet strategy
you don't have to make the change all at once		diet strategy
you have to get your mind and your brain on that, and constantly remind yourself		diet strategy
small meals, I eat off of a saucer place, that's my plate		diet strategy
if there's no room on it, then I don't need it		diet strategy
so I know to stay away from it		diet strategy
just the mindset		diet strategy

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
you can eat a piece of fruit and you can go the rest of the day	is a kind of	diet strategy
willpower		diet/salt problem
willpower/temptation		diet/salt problem
If I didn't have a TV, I probably wouldn't sit in there, and I'd probably would wanna get on the bike		exercise hindrance
If I had that buddy plan again		exercise need
I just need to get another bike so he can get on it, so I can get on mine		exercise need
I used to do some volunteer stuff		exercise need
Flexible scheduling		exercise need
if I had my own treadmill		exercise need
someone to walk with		exercise need
if I felt better		exercise need
if my heart was at 100% again, I would still probably exercise, because I know that's what is causing it to get better		exercise need
the right equipment		exercise need
I never found it easy		exercise problem
We have a tendency to sit in the living room and watch TV		exercise problem
I sit on the couch and then my butt just doesn't want to get up		exercise problem
I'm just not motivated		exercise problem
[lack of] Motivation		exercise problem
the weather		exercise problem
just the weather		exercise problem
when I'm too short of breath, I just can't		exercise problem
there's a limit to what I can do		exercise problem
a bad headache, and you're halfway dizzy, so you just don't get out there and do it		exercise problem
the weather here		exercise problem

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
When I'm on my bike he encourages me to continue	is a kind of	exercise strategy
There's a program that I watch on TV while I'm on my bike		exercise strategy
sometimes I take my dogs		exercise strategy
try to walk every day		exercise strategy
I have been trying to use the treadmill a little bit		exercise strategy
I always walked to get the mail		exercise strategy
if I take the trash out that way, see, it's a pretty little walk back and worth that way		exercise strategy
I've always had a little garden		exercise strategy
the idea that I wanna live and my heart needs to get better		exercise strategy
it's just that you have to have the drive		exercise strategy
I just parked way down here at the parking lot and walked up		exercise strategy
pain pills		exercise strategy
I gotta walk the dogs		exercise strategy
a day-to-day routine		exercise strategy
yoga's helped with me a lot to do that, you kind of listen to what the body's telling you		exercise strategy
so now, I usually go to Florida to my other daughters		exercise strategy
if I got any sicker, I'd probably try harder		exercise strategy
Yoga has taught me how to breathe as you exercise, so that does help. Breathing exercises do help.		exercise strategy
I continue to exercise and figure out your won diet		exercise/diet strategy
It [water] smelled like bleach, then I couldn't drink it anymore		fluid hindrance
If I had someone go get me water for me while I was at work		fluid need

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
I've thought about asking the boss a couple of times when it was really busy. And he would	is a kind of	fluid need
If we didn't have so much gunk in our faucet water		fluid need
At work, it's difficult to get up and get the water		fluid problem
I like my water cold, so if it doesn't have ice in it, then I don't really want it		fluid problem
Fluid intake is very important		fluid problem
I carry it [water] with me a lot		fluid strategy
I keep it [water] on my desk at work		fluid strategy
He's been reminding me to drink my juice		fluid strategy
But I drink it anyway		fluid strategy
If we go out to eat, I drink water with my meal		fluid strategy
I'd drink water if I drank alcohol, that was the only time		fluid strategy
I try to keep a bottle of water in my car		fluid strategy
I know how much liquid he can have and what he can't		fluid strategy
Planning		going outside strategy
if I don't care of myself, then no one else is gonna take care of me		lack of support strategy
wouldn't have my medication handy for me to get to		medication hindrance
not have my water to drink		medication hindrance
being out with a friend and forgot my medication at home		medication hindrance
have his medicine delivered right here to the door		medication need
when I'm having those dizzy spells, if somebody isn't there to get my water		medication need

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
I wound up with no medicine for a little bit run out and not have money to go get 'em, [sic] sometimes	is a kind of	medication problem  medication problem
the sorted pill box so I don't take too much of one pill routine I just know it's there and I gotta take it taking my vitamins, I think my medication works better I got them pill boxes I set up weekly		medication strategy medication strategy medication strategy  medication strategy medication strategy
if he didn't have it at all I think just being healthy would be ideal the situation would not be here If I didn't have the disease if I felt unsafe  if I had fallen, or an accident had happened around the house, then I wouldn't have the desire to do this  family come over, and that would alter my schedule not a bad heart if I didn't have a bad heart, I'd probably do a lot of things differently  now all of a sudden they're throwing all this stuff at you that you've gotta do, and it's overwhelming, and not say the least, it's very, very overwhelming.		overall hindrance overall hindrance overall hindrance overall hindrance overall hindrance  overall hindrance  overall hindrance overall hindrance overall hindrance  overall hindrance
it'd be nice if a doctor would come to the house and we wouldn't have to get out  it'd be nice to have someone come and pick him up and take him to his doctor's appointments it's a job, its' a job, but we do it [parking] because you can't alter anything having the time to do it it's all in the schedule unlimited money		overall need   overall need overall need overall need overall need overall need overall need



<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
out west, yeah you could 'cause everybody discusses and you don't see a lot of that	is a kind of	overall need
people out there is more geared to taking care of their self		overall need
I think a lot of it's the culture, whichever area you're in		overall need
the best thing that ever happened was me moving out west, staying out there so long, and learning from those people of what to do		overall need
it's a therapeutic thing, and I think you gotta change your mind		overall need
I think it should be in stowed in high schools, that they have to go through a nutrition class		overall need
if people would talk to each other more, like if we had a group, to get a group together, that could talk every once a week about what they do...		overall need
I also think that congestive heart failure, diabetics and emphysema and COPD, it all goes together in one		overall need
every individual needs to put education with it		overall need
some days he just doesn't feel good		overall problem
sometimes this just comes up		overall problem
cause it's the very same stuff [as COPD]		overall problem
I don't even know it's there		overall problem
I don't have to do anything, as far as I know there's no prohibitive situations		overall problem
I just don't have the strength or whatever to do it		overall problem
just not having the desire		overall problem
it's a culture shock back here more than anything		overall problem
well, if I'd took care of myself back when I was younger, I wouldn't be in this position today		overall problem

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
it's just kind of a way of life	is a kind of	overall strategy
you learn to adapt to it		overall strategy
everything happens first thing in the morning		overall strategy
I just have a regular schedule		overall strategy
there's a regimen and I follow the regimen		overall strategy
you just get up and do whatever you need to do		overall strategy
so there's a way I do things, and as long as you don't skip a step, I'm alright		overall strategy
I've got to do it		overall strategy
you can beat it but you've got to have the drive to want to beat it		overall strategy
Makes it easier 'cause being on the West Coast, we don't have all these fast foods.		overall strategy
it's important to keep a journal of what you eat, what you did that day, how far you've walked, if you went to the gym or not, what times you spent there		overall strategy
it just makes it hard everyday. It's just hard		overall strategy
now that you're on the right track and going downhill with the weight, it makes your heart stronger as you do the things that you're doing		overall strategy
it's not something I wanted to do, it's something I had to learn to do		overall strategy
when you have congestive heart failure, you're gonna have to make a lifestyle change		overall strategy
I wish more doctors were like that. They flat out tell you		overall strategy
I wouldn't have to have a pacemaker		pacemaker hindrance
my kitten		rest hindrance
just being at home where I can do what I want		rest need
be on my own schedule		rest need

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
you wouldn't have anybody in your house but you	is a kind of	rest need
I just get tired and gotta rest		rest strategy
If I could not crave salt		salt hindrance
it depends on who cooks it and where I get it from, things that they add into it		salt hindrance
same [just being at home and cooking well] if they would educate people about what salt can do later on in life		salt need salt need
I don't salt stuff when I cook for him, but it's just what I'm cooking same thing [being out]		salt problem salt problem
it's difficult 'cause they put salt in everything because the food tastes better, it does		salt problem salt problem
it has become part of how I am		salt strategy
I used to eat all potato chips. I don't do that no more.		salt strategy
I love ham, but I barely ever have more than a bite, because of the sodium in it		salt strategy
I've kinda replaced my salt for pepper and cayenne pepper and stuff like that because I know the sodium is really bad I use Dash, Mrs. Dash		salt strategy salt strategy salt strategy
but after you do it three or four months, your body's accustomed to it, and I think you gotta change your brain into thinking		salt strategy
I can tell if I eat something that I know I shouldn't		salt strategy
you've got to keep a journal. I keep a journal on things I eat when I do eat salt...I get sweats		salt strategy salt strategy

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
Mrs. Dash makes one that looks white as salt, so to me I think I'm putting salt on there, and I'm really not	is a kind of	salt strategy
if I could stay home		sleep/rest need
the traffic [noise] out in the street		sleep/rest problem
neighbors		sleep/rest problem
company		sleep/rest problem
I you have to go someplace		sleep/rest problem
that messes your routine up		sleep/rest problem
something that breaks up the routine, or someone comes to visit you		sleep/rest problem
if I do too much exercise, then you have enough aggravation that you don't wanna sleep, you're not able to sleep as good.		sleep/rest problem
if you have to do someplace		sleep/rest problem
sometimes you get involved with stuff or have tests or something, and you're too keyed up to relax		sleep/rest problem
it's when I have to run and do stuff, it wears me out		sleep/rest problem
I'd have something to do that I couldn't rest		sleep/rest problem
if we were out of town		sleep/rest problem
out doing something for the day		sleep/rest problem
whatever I need to, I'll sleep in		sleep/rest strategy
I don't have any interruptions		sleep/rest strategy
if I didn't have heart failure, yeah, I wouldn't watch it [salt] at all		sodium hindrance
we watch a lot of TV, movies and stuff		staying inside strategy
[grandbaby] breaks the monotony a little bit		staying inside strategy
you have to dress for it		staying inside strategy
medical bills		stress hindrance
my friend, mike		stress hindrance

<b>Included Term</b>	<b>Semantic Relationship</b>	<b>Cover Term</b>
More money	is a kind of	stress need
Less work		stress need
Have my housekeeper come more often		stress need
stay away from certain people		stress need
 You can't just walk off		stress problem
Finances		stress problem
continued drama		stress problem
a continuance of a situation that I want to control but I can't		stress problem
 I just have to take a couple of deep breaths		stress strategy
Just walk away from stuff		stress strategy
He keeps things a little lighter		stress strategy
He pesters me and I know it's just fun for him, and I end up laughing		stress strategy
I literally just had to walk away from her [mother]		stress strategy
I don't have any problems with support		stress strategy
walk, talk, listen to music		stress strategy
I make myself chill		stress strategy
you need to take time for yourself. I don't care if it's two hours in the evening, figure it out.		stress strategy
 I can't leave him very long at a time		support hindrance
 It takes me a long time to realize		support problem
My past		support problem
I have to remind myself because I've been in a lot of, what I would classify as abusive relationships, mental abusive		support problem
He's very supportive		support strategy
 if I were thin and svelte		weight hindrance
 same thing [if the configuration of our bedroom were a little bit different]		weight need

**Included Term****Semantic Relationship****Cover Term**

it's right under there and I look at it first  
thing in the morning. So yeah, I go ahead  
and do it.

is a kind of

weight need

I'm supposed to, but I don't every day 'cause  
I don't like to

I watch the food go in my mouth

it's right in the same area

same reason [if I'm on vacation or out of  
town for the weekend]

being gone

weight problem

weight problem

weight problem

weight problem

weight problem

I have an electronic scale provided by  
Boston Scientific.

the scale is battery operated

I generally weigh ... about the same time of  
day

it's the idea I wanna see what I've done

it's like an accomplishment

it wasn't all drugs that did that, it was a  
lifestyle change that I had to make

weight strategy

weight strategy

weight strategy

weight strategy

weight strategy

weight strategy

you're gonna have to get up and help  
yourself, doctors can only help you so much

it's just out of habit now

Boston Scientific sent me the scale

is a kind of

weight strategy

weight strategy

weight strategy

I've got big ol' [sic] wings now

weight loss problem

## Appendix C



Office of Research Compliance  
Institutional Review Board

October 6, 2016

### MEMORANDUM

TO: Somer Overshon  
Kit Kacirek

FROM: Ro Windwalker  
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 16-09-113

Protocol Title: *Assessing Patient Perceptions of Self-Care: Examining Chronic Disease in a Rural Underserved Area*

Review Type: ☒ EXEMPT ☐ EXPEDITED ☐ FULL IRB

Approved Project Period: Start Date: 10/05/2016 Expiration Date: 10/04/2017

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<https://vpred.uark.edu/units/rscp/index.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

**This protocol has been approved for 13 participants.** If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior* to implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 109 MLKG Building, 5-2208, or [irb@uark.edu](mailto:irb@uark.edu).